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**Exploring fatigue in Inflammatory Bowel Disease as experienced by individuals
A descriptive phenomenological study**

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**Exploring fatigue in Inflammatory Bowel Disease
as experienced by individuals – a descriptive
phenomenological study**

Wladyslawa Janina Czuber-Dochan

Thesis submitted for the degree of Doctor of Philosophy

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Florence Nightingale Faculty of Nursing and Midwifery

King's College London

“Fatigue has always been an elusive creature. Poets write about it, newspapers argue about it, patients suffer from it, and scientists occasionally study it”

(Simon Wessely, 2005: p XI in DeLuca, 2005)

Abstract

Inflammatory bowel disease (IBD) affects 300,000 people in the United Kingdom (UK). The condition is characterised by periods of remission and relapse. Forty percent of people with IBD in remission and 72 - 86% of people with active IBD report fatigue to be their most troublesome symptom. IBD-fatigue affects people's daily functioning and impacts on their quality of life. However, there is limited understanding of the concept of fatigue and the impact that fatigue has on the everyday life of people with IBD. There are no previous studies exploring how people try to manage IBD-fatigue on a daily basis.

Aims

This study aims to explore the concept of fatigue as experienced by people with IBD, what impact fatigue has on their lives, and how they manage it.

Methods

Descriptive phenomenology was used to achieve the aims of the study. One-off in-depth interviews were conducted with twenty participants. Interviews were digitally recorded and transcribed verbatim. Data were analysed using Moustakas' method (1994). This involved analysing the data at individual and group levels for textural and structural descriptions.

Results

Five main themes, with many textural and structural sub-themes were identified. A wide range of terminology, including metaphors and similes, were used to describe fatigue reflecting its complicated and complex nature. Fatigue was presented as invisible, unpredictable, with constantly fluctuating daily patterns and severity. This made reporting fatigue difficult and at times lead to participants being challenged about its authenticity. The array of physical, psychological, cognitive and situational factors were perceived to contribute to fatigue, and different methods (e.g. sleep and rest, pacing, energy preservation, exercise, stress reduction, asking for help) were attempted by participants to manage fatigue. Most methods were not used systematically, possibly resulting in their apparently limited effectiveness. Impact of fatigue was perceived as negative, with participants constantly comparing their life and themselves as they were before fatigue and

how much they have lost. They felt that fatigue is in control of their life and each day they had to fight another battle to defeat fatigue. Participants felt imprisoned in their fatigued unreliable body leaving them frustrated, isolated and lacking self-confidence. They reported loss of self and self-identity, resisting to accept the ‘new fatigued me’.

Conclusion

Due to its complicated and complex nature, IBD-fatigue is not fully understood by individuals affected by it, and they have difficulties clearly explaining it to others.

The invisibility of IBD-fatigue often leads to its existence being questioned by self and others. The negative and debilitating impact of IBD-fatigue affects all aspects of an individual’s life.

Individuals affected by IBD-fatigue need support from healthcare professionals to help them to understand and manage this complex symptom. The findings from this study need to be taken into consideration by healthcare practitioners involved in the care of IBD patients. To fully understand the phenomenon of fatigue a longitudinal study is required to explore fatigue over time.

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Abbreviations and Acronyms

Anti-TNF α	Anti-Tumour Necrosis Factor Alpha
BLF	Big Lottery Fund
BNI	British Nursing Index
CASP	Critical Appraisal Skills Programme
CD	Crohn's Disease
CFS	Chronic Fatigue Syndrome
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CIS	Checklist Individual Strength
COAD	Chronic Obstructive Airways Disease
COPD	Chronic Obstructive Pulmonary Disease
DoH	Department of Health
EFCCA	European Federation of Crohn's and Colitis Association
EMBASE	Excerpta Medica Database
FACIT-F	Functional Assessment of Chronic Illness Therapy-Fatigue Scale
FIS	Fatigue Impact Scale
FL	Fatigue Level
GP	General Practitioner
HCPs	Healthcare Professionals
HIV	Human Immunodeficiency Virus
HRQoL	Health Related Quality of Life
IBD	Inflammatory Bowel Disease
IBDQ	Inflammatory Bowel Disease Quality of Life Questionnaire
IBS	Irritable Bowel Syndrome
ME	Myalgic Encephalomyelitis
MEDLINE	Medical Literature Analysis and Retrieval System Online
MeSH	Medical Subject Headings
MFI	Multidimensional Fatigue Inventory
MS	Multiple Sclerosis
NADH	Nicotinamide Adenine Dinucleotide and Hydrogen
NHS	National Health Service
PHRU	Public Health Research Unit
QOL	Quality of Life
RA	Rheumatoid Arthritis
RCT	Randomised Controlled Trials
SCCAI	Simple Clinical Colitis Activity Index
SF-36	Short-Form-36
SSCI	Social Science Citation Index
SCI	Social Citation Index
UC	Ulcerative Colitis
UK	United Kingdom
USA	United States of America

Chapter 1 Introduction and organisation of the thesis

1.1 Introduction

In Northern Europe and the United States an estimated 3.6 million people are affected by inflammatory bowel disease (IBD) and more cases are being diagnosed each year partly due to increasing prevalence and better diagnostic procedures. Several studies have identified fatigue as one of the leading concerns for people with IBD (Drossman *et al.* 1989, Maunder *et al.* 1997, Casati *et al.* 2000, De Rooy *et al.* 2001) with 41-48% of patients complaining of fatigue when IBD is in remission and 72-86% in active disease (van Langenberg & Gibson 2010, Czuber-Dochan *et al.* 2013a). Patients' most commonly reported concerns relate to low levels of physical energy, low motivation and challenge in achieving their full potential (De Rooy *et al.* 2001). In a study of concerns reported by 447 Crohn's disease patients during regular follow up visits, the three concerns most frequently mentioned were possibility of having an ostomy, energy level and bowel control (Stjernman *et al.* 2010). However patients' complaints of fatigue are seldom addressed by healthcare professionals due to limited understanding of the symptom and lack of known effective interventions for its management (Czuber-Dochan *et al.* 2013a, Czuber-Dochan *et al.* 2014a).

This thesis presents a study investigating the experience of fatigue reported by people diagnosed with inflammatory bowel disease (IBD). The aim of this chapter is to:

- Provide background to my developing interest in IBD-fatigue, and reasons for undertaking the study
- Introduce a definition and theories of fatigue
- Provide an outline of the thesis and a brief introduction to the chapters.

1.2 Background to undertaking the study

I first became interested in IBD-fatigue through my collaboration with Christine Norton, Professor of Gastrointestinal Nursing, and the work that I undertook with her for the Crohn's and Colitis UK charity in 2008-09. The work involved researching patients' self-reported experience of IBD-fatigue and used focus group interviews (Czuber-Dochan *et al.* 2013b). The study identified that fatigue was an inextricable part of daily life and had a

debilitating effect on the physical, social and emotional wellbeing of participants. This was the first ever exploratory study on people's experience of fatigue in IBD, indicating its multifaceted nature and pervasive impact. Further investigation was recommended, using individual in-depth interviews for a fuller exploration of people's unique experience of fatigue (Czuber-Dochan *et al.* 2013b).

There is an abundant literature describing the pathophysiology and treatment of IBD (Korzenik & Podolsky 2006, Hanauer 2009, Carter *et al.* 2011, Khanna *et al.* 2013). However, there is little empirical evidence about people's subjective experience of living with it and how associated symptoms affect their lives (Sainsbury & Heatley 2005). People with IBD encounter a variety of symptoms including diarrhoea, pain, abdominal bloating and fatigue (Joyce *et al.* 2008, Mowat *et al.* 2011, Targan *et al.* 2003). These symptoms have been described as subjective, unpleasant and distressing (Minderhoud *et al.* 2003). This thesis, utilising descriptive phenomenology, presents a detailed description of fatigue. Thorough understanding of the symptom and its impact on people's lives is important for both research and clinical practice, if evidence-based patient-centred care is to be provided.

The impetus for my doctoral work originates from a larger programme of studies on IBD-fatigue developed with, and conducted for, Crohn's and Colitis UK, July 2010 – July 2014. Further details regarding the entire programme and its aims are presented in Box 1-1 and can also be found at www.fatigueinibd.co.uk (Crohn's and Colitis United Kingdom.). This was a collaborative programme between researchers from King's College London, University College London and Cambridge University Hospitals; with Crohn's and Colitis UK acting as commissioner and fund holder. The Big Lottery Fund (BLF) provided the funding.

I have been involved in the project since the study design and development of the BLF grant application. I am a named applicant on the grant application and I have written the proposals for four out of seven parts of the study: work packages two, three, four and seven (Box 1-1).

In view of my prior work exploring IBD-fatigue using focus group interviews and my preparatory reading, I determined that further qualitative investigation of IBD-fatigue utilising in-depth interviews with individuals was the way forward to develop better understanding of this symptom.

Box 1-1 BLF funded programme of studies in IBD-fatigue

Work Package One: Baseline and follow up survey of IBD-fatigue awareness, help seeking and services available - to answer **Questions:** 1) What is the current awareness of IBD-fatigue among Crohn's and Colitis UK members and healthcare professionals? 2) Does the project change the level of awareness of fatigue in Crohn's and Colitis UK members and healthcare professionals?

Work Package Two: Description of IBD-fatigue and coping mechanisms used by people with IBD - to answer **Questions:** 1) What is the experience of fatigue reported by people with IBD? 2) What coping mechanisms are used by people who live with IBD-fatigue?

Work Package Three: Literature review to identify instruments/items suitable for use with people with IBD - to answer **Questions:** 1) Which fatigue scales may be suitable for use with people with IBD? 2) Which approaches to fatigue management are successful in other conditions?

Work Package Four: Psychometric testing of the new IBD-fatigue specific measure - to answer **Question:** Can an IBD-fatigue assessment scale measure fatigue and its impact on individuals with IBD?

Work Package Five: Develop and evaluate two interventions to improve fatigue in IBD - to answer **Question:** Will either or both tested interventions improve fatigue in IBD?

Work Package Six: To determine if people with IBD-fatigue have undiagnosed medical conditions that could be treated to improve their fatigue - to answer **Question:** Do people with IBD and fatigue have undiagnosed medical conditions that if treated could improve fatigue?

Work Package Seven: Description of fatigue and its impact on lives of people diagnosed with IBD as perceived by healthcare professionals - to answer **Question:** What is healthcare professionals' perception of IBD-fatigue and its impact on the lives of people diagnosed with IBD, and their strategies for assessing and managing fatigue in clinical practice?

Until that point, IBD-fatigue was not sufficiently described, and its understanding was based on information collated predominantly via quantitative methods (e.g. questionnaires). Therefore my doctoral work aims to counter-balance the current understanding of fatigue by providing a description, as experienced by people with IBD. Prior to commencing my work on the programme of studies for Crohn's and Colitis UK, I

had already registered for my post-graduate study and prepared the research proposal which constituted part of the application for funding submitted to BLF.

1.3 Researcher's personal role in the programme of studies

My role as a Nurse Research Fellow on the project involved day-to-day management of Work Packages Two, Three, Four and Seven, recruitment of participants, data collection, analysis and dissemination of results in the form of national and international conference presentations, and peer reviewed publications. Other members of the team contributed to the work in the supervisory (Professors Norton and Ream) and advisory (Steering Group Committee) capacity. All four Work Packages were successfully completed on time and on budget. The outputs from the research programme and the publications are presented in Appendix I.

My doctoral work and thesis presented for examination relates to Work Package Two and extends and elaborates what was required for the Crohn's and Colitis UK work; namely to describe people's experience of fatigue to generate items for questionnaire development (Work Package Four), and to identify methods used to manage fatigue to inform the development of interventions for preliminary testing (Work Package Five). My doctoral work has been performed independently, under the direction of my supervisors, and explores in depth the nature and impact of fatigue as experienced by people with IBD.

Throughout the thesis I predominantly refer to myself as 'researcher' to demonstrate my role in the study, or 'PhD researcher' to acknowledge my junior and developmental status. The active form of 'I' is used only where reflective comments are provided.

1.4 Definition of fatigue

The definitions and language used to describe IBD-fatigue are analysed in detail in Chapter 2, Section 2.3. However, it is important to gain some clarity of the symptom of fatigue right from the study outset. In literature on chronic conditions, fatigue has been defined as an 'extreme and persistent sense of tiredness, weakness, or exhaustion' (Dittner *et al.* 2004) (p157), which can be physical or mental or both, and is not easily resolved by sleep and rest (Arnett & Clark 2012). 'Symptom' has been defined as a subjective evidence of

disease, in contrast to a ‘sign’ which is an objective indication of a disease that can be observed by others (The Oxford English Dictionary 2012).

1.5 Theories and conceptual perspectives of fatigue

The term fatigue originates from French *‘fatiguer’* to ‘tire’ or *‘fatigue’* meaning ‘weariness’, or from Latin *‘fatigare’* meaning to ‘cause to break down’ (The Oxford English Dictionary 2012). Fatigue is a commonly experienced symptom by most people at some point in life and can usually be related to excessive physical activity, stress or ill health. Therefore, fatigue can be a reaction to both physical and mental exertion (Pawlikowska *et al.* 1994, van't Leven *et al.* 2009), and the outcome of pathological processes (McSweeney *et al.* 2003, Kralik *et al.* 2005, Lerdal *et al.* 2011).

The term fatigue has been widely used and studied across different disciplines. In industry, fatigue relates to ergonomics and macroscopic cracks weakening metal performance, known as metal fatigue (Murakami & Miller 2005). In sport science, fatigue relates to strength loss due to muscle and nerve fibre fatigue in optimising athletic excellence (Millet & Lepers 2004). In professions with shift work patterns (e.g. nursing, military, aviation) the impact of work schedules on fatigue has been investigated as a factor reducing physical productivity and mental concentration (Caldwell & Caldwell 2005, Muecke 2005, Barker & Nussbaum 2011, Yuan *et al.* 2011). The use of the term fatigue in a variety of contexts, lay and professional, poses challenges in understanding its meaning.

Medical interest in the phenomenon of fatigue stems from the fact that it is frequently reported by individuals as one of the first symptoms of physical or mental illness (Minden & Reich 1983, Dittner *et al.* 2004, Radbruch *et al.* 2008, Kirshbaum *et al.* 2013). In these circumstances fatigue may be seen as the result of pathophysiological process and may have a warning, protective function. In acute conditions fatigue can precede and follow the illness (McSweeney *et al.* 2003, Vollmer-Conna *et al.* 2004, Lerdal *et al.* 2011). In chronic conditions on the other hand, fatigue can lead to a long-term physiological decrease of energy reserves and result in functional impairment (Bol *et al.* 2009, Al-shair *et al.* 2011, Fink *et al.* 2012). Therefore, an approach incorporating protective and debilitative aspects of fatigue should be taken into account when assessing a patient’s trajectory of the illness.

Some 15-20% of the general population report fatigue as an effect of prolonged or excessive physical or mental activity, or both (Pawlikowska *et al.* 1994, Loge *et al.* 1998, Dagfinrud *et al.* 2005, van't Leven *et al.* 2009). This type of fatigue, arising from normal and desired activities, is often referred to as acute fatigue or normal fatigue. It is usually of short duration and can be moderated or relieved by change of behaviour such as rest, sleep and improved nutrition. Fatigue arising from the pathological process or psychological disorder of longer duration is often referred to as chronic fatigue. This type of fatigue can be characterised by reduced levels of energy and motivation, and does not normally improve after sleep, or only improves temporarily (Piper 1993, Glaus *et al.* 1996, Cahill 1999). Fatigue could be also classified according to its location as peripheral (lack of muscle strength and weakness) and central (incorporating memory and concentration difficulties) (Gibson & Edwards 1985, Bass 1989).

Fatigue has been portrayed in the literature as a phenomenon consisting of five dimensions: (1) behavioural dimension (intensity of the experience impacting on people's daily functioning); (2) sensory dimension (manifested through physical, emotional and mental symptoms); (3) cognitive dimension (affecting concentration, memory and cognition); (4) affective dimension (demonstrated by mood and emotional well-being); and (5) temporal dimension (manifested by onset, pattern and duration) (Wessely *et al.* 1998). The International Classification of Diseases Code for fatigue also presents fatigue as a collection of physical, cognitive and emotional symptoms affecting completion of daily tasks (Haney *et al.* 2015).

1.6 Organisation of the thesis

This chapter gives an introduction to the background, purpose and the structure of the thesis. Chapter 2 provides a critical discussion of the research literature currently available regarding IBD-fatigue; namely the definition of fatigue, its prevalence, types and contributing factors. The chapter also explores current methods for assessing and managing fatigue as well as the impact it has on individuals with IBD. In line with descriptive phenomenology, this information was collated and analysed when the study data were already collected and partly analysed. Chapter 3 presents information on IBD, its diagnostic tests, treatment options, and how different symptoms of IBD impact on people's life and its quality, providing context for the study of fatigue in IBD.

A meta-synthesis of literature on fatigue in other chronic conditions is presented in Chapter 4. The chapter explores the disease-related fatigue and methodologies used to study the symptom in other (selected) chronic conditions, where more extensive research is available, (cancer, multiple sclerosis, rheumatoid arthritis). Again, it is important to clarify that the material included in this chapter was prepared after interview data were analysed and written in draft form. Although the information presented in Chapters 2 and 4 precede, and in some cases pre-empt some of the study findings presented in later chapters, it is important from a methodological point of view, to elucidate the order of events and research steps to the reader. The reason for presenting Chapter 2 and Chapter 4 in this thesis ahead of study findings was pragmatic, and aimed to introduce and familiarise the reader with the background information about IBD-fatigue (Chapter 2) and descriptions of fatigue and the fatigue experiences in other chronic conditions (Chapter 4). Chapters 2 and 4 also provide rationale and confirm that the symptom of IBD-fatigue is yet to be fully understood.

Chapter 5 presents the epistemological underpinnings of the research process and the description of methodology and methods employed during the course of the study. Descriptive phenomenology was selected to best serve the purpose of the study, namely, to illuminate the essence of fatigue experienced by people diagnosed with IBD. To achieve this, twenty individuals diagnosed with IBD and self-diagnosed with IBD-fatigue were selected and interviewed in-depth.

The first five chapters provide context to the study of IBD-fatigue and the description and rationales for the methodology used for its investigation, while Chapter 6 provides a description of the practical operation of the data analysis process underpinned by examples of each analytical stage. Information presented in Chapters 5 and 6 also provides an audit trail, reflecting the systematic process and the thorough rigorous approach to data analysis, on the basis of which the study quality can be assessed. Moustakas' method (1994), employed to analyse data, requires two levels of analytical process, textural (giving the description of the studied phenomenon) and structural (looking for possible explanation or relationships between different elements of the experience).

The texture of the experience (description) and the structure (explanation or meaning) of that experience was analysed for each individual participant and then synthesised into a composite (group) experience. The findings of the study are presented and preliminarily discussed in Chapters 7, 8 and 9. Chapter 7 provides a description of fatigue and analysis of the terms used to depict the experience of fatigue, its pattern, types and severity. Chapter

8 presents a variety of factors associated with fatigue and array of methods used by individuals to deal with it; while Chapter 9 illustrates the types of fatigue and the extent of its impact on individuals' lives, and describes how participants' lives are affected by fatigue. The data presented in these three chapters are the results of analysis of individual textual and structural descriptions on the basis of which a composite description of the essences and meanings of fatigue were developed.

The final chapter, Chapter 10, offers a discussion and synthesis of the major findings of this research alongside research evidence in other chronic conditions obtained through the previous literature reviews and the wider, relevant literature. This allows for the essence of IBD-fatigue experience to be discussed in light of the new insight gained from the study. The methodology and methods employed in this work are critiqued and evaluated. Recommendations for further research, clinical practice and education are made. The limitations of the study are considered and conclusions are drawn. The dissemination plan for research output in the form of publications and conference papers is presented.

Chapter 2 Fatigue in inflammatory bowel disease

2.1 Introduction

IBD is a chronic inflammatory condition of the gastrointestinal tract with a remitting and relapsing presentation. The most commonly recognised forms of IBD are Crohn's disease (CD) and ulcerative colitis (UC), and fatigue is a common symptom in both conditions. More information on IBD, its prevalence, clinical signs and symptoms, diagnostic procedures and clinical management is presented in Chapter 3.

This chapter explores the current body of knowledge on IBD-fatigue, aiming to:

- Provide background information to the study
- Provide information on the literature review process
- Critically review the evidence on IBD-fatigue
- Critique the language and definitions of fatigue
- Identify gaps in the evidence, thus provide the rationale for this study.

Fatigue in IBD has been reported to be multidimensional and multifaceted, impacting on individuals' everyday functioning and reducing their quality of life (Drossman *et al.* 1989, Hjortswang *et al.* 1998, Cohen 2002). For a number of years fatigue has been recognised as one of the most debilitating symptoms and a leading concern of people diagnosed with IBD (Drossman *et al.* 1989, Casati *et al.* 2000, De Rooy *et al.* 2001, Stjernman *et al.* 2010); however, to date it has attracted little interest and attention in research and clinical practice (van Langenberg & Gibson 2010). The first textbook specifically written for nurses working with IBD patients allocated less than a page to fatigue (Whayman *et al.* 2011).

The first systematic review of literature on IBD-fatigue which set to determine the prevalence and pattern of fatigue, identified only 10 studies (including two studies in children) published between 1999-2009 (van Langenberg & Gibson 2010). All of the studies were of quantitative design, with no qualitative studies reporting the subjective experience of fatigue in people with IBD. The review authors concluded that there is an urgent need to better understand fatigue before interventions targeting the symptom can be developed (van Langenberg & Gibson 2010). Recent *Guidelines for the management of inflammatory bowel disease in adults* (Mowat *et al.* 2011), published in the United

Kingdom (UK), also recommended that fatigue needs to be researched further if patients are to receive quality care for this distressing symptom.

Taking the above recommendations on board and the fact that further research was published since Van Langerberg & Gibson's (2010) review, a subsequent review of literature was conducted by the author of this thesis, which aimed to establish what is known about the symptom of fatigue, its experience and impact on lives of people with IBD.

The specific questions addressed by the review were:

- i) How do people with IBD-fatigue describe their experience of fatigue?
- ii) What factors are associated with the presence and severity of IBD-fatigue?
- iii) What do people with IBD, and healthcare professionals, do to try and manage IBD-fatigue?

Although the literature review was conducted when the current study was already in progress, identifying the gaps in knowledge on IBD-fatigue helped to firmly demonstrate the need for the study and position it against the existing evidence.

2.2 The literature search strategy and summary of papers included in this review

Multiple databases (MEDLINE, CINAHL, EMBASE, PsycInfo, BNI, Cochrane and the Web of Science including Science Citation Index and Social Science Citation Index) likely to publish papers on IBD-fatigue were individually and systematically searched (Booth *et al.* 2012, Gough *et al.* 2012). Medical subject headings (MeSH), free-text searching and truncation were used to maximise citation retrieval (Hart 1998, Cooper 2010). Variations of the search terms related to fatigue, IBD, fatigue management and healthcare professionals (HCPs) were developed. To improve the number of retrieved citations, no lower time limit was set, with the most recent search performed on 3rd August 2012. Searches were limited to 'humans', 'all adults', 'primary research' and 'English language' publications as there was no scope for translation. The searches yielded 632 references in total. The PRISMA statement for reporting systematic reviews (Moher *et al.* 2009) was followed to select the studies that met the inclusion criteria (Figure 2-1).

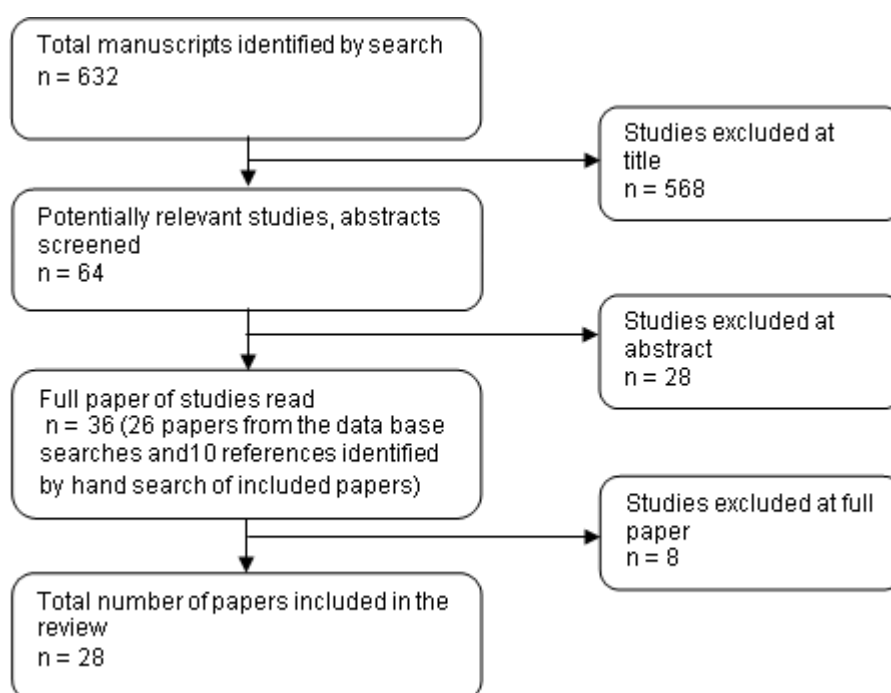


Figure 2-1 Citation retrieval and handling process

This resulted in 28 papers being included. Studies of any design (qualitative, quantitative or mixed methods), published in English were included if IBD-fatigue was reported. Abstracts, commentary or review papers were excluded. The studies' quality was assessed using the Critical Appraisal Skills Programme (CASP) guidelines specific to the study design (www.casp-uk.net). Only three studies (five publications) were classified as high quality (Romberg-Camps *et al.* 2010, Jelsness-Jørgensen *et al.* 2011a, Jelsness-Jørgensen *et al.* 2011b, Bager *et al.* 2012, Jelsness-Jørgensen *et al.* 2012a). Due to a limited number of publications on IBD-fatigue, no studies were excluded based on their quality. The findings from the reviewed papers have already been synthesised and published (Czuber-Dochan *et al.* 2013a). A copy of the paper providing more detailed information on the process of searching, papers selection, results of quality assessment is presented in Appendix II and the extracted data in Appendix III. A summary of the findings is presented in this chapter and an update of literature published since the review is presented in Chapter 10, Discussion.

Among the reviewed papers (n=28) there were cross-sectional surveys (n=18), randomised control trials (RCTs) (n=5), population-based prospective studies (n=2), case study design (n=1), and secondary data analysis (n=2), of which one was quantitative and one qualitative. The only qualitative paper presented a secondary data analysis, collected as part of a larger study exploring individuals' subjective experience of living with IBD. In an online survey, as well as completing a variety of questionnaires (e.g. Health Related Quality of Life - HRQoL, Inflammatory Bowel Disease Quality of Life - IBDQ), participants were asked to provide information to one open-ended question: 'How has IBD affected your daily activities?' (Wolfe & Sirois 2008:879). Reduced physical energy and/or vitality were identified as one of six themes. Participants reported fatigue, difficulties to complete tasks and an increased need for sleep; however, the information provided was very limited. There is, to date, no other qualitative work investigating this issue.

2.3 Definitions and language used to describe fatigue

A majority of the reviewed studies (n=16) did not define the concept of fatigue (Appendix III). Three studies identified the fatigued population as 'the 95 percentile of the score on the general fatigue scale of the healthy control group' (Minderhoud *et al.* 2003, Minderhoud *et al.* 2007, Romberg-Camps *et al.* 2010). Seven studies (nine papers) (Hauser *et al.* 2005, Bol *et al.* 2010, Graff *et al.* 2011, Romkens *et al.* 2011, Tinsley *et al.* 2011, Jelsness-Jørgensen *et al.* 2011a, Jelsness-Jørgensen *et al.* 2011b, Bager *et al.* 2012, Jelsness-Jørgensen *et al.* 2012a) provided a more comprehensive definition. IBD-fatigue was defined as a 'subjective experience of reduced physical and/or mental energy and vitality' (Hauser *et al.* 2005:1), a feeling of 'tiredness, reduced energy levels, reduced muscle strength, and cognitive impairment' (Jelsness-Jørgensen *et al.* 2011a:1564), or 'an overwhelming sense of tiredness, lack of energy and feeling of exhaustion with impaired physical and/or cognitive functioning, incorporating both the sense of physical depletion as well as interference' (Graff *et al.* 2011:1882). Romkens *et al.*, (2011) defined fatigue as 'unpleasant, unusual, abnormal, excessive whole-body tiredness, disproportionate to or unrelated to activity or exertion' (p.333).

The definitions cited in the IBD-fatigue papers were adopted from studies on fatigue in cancer, multiple sclerosis (MS), hepatitis C and chronic fatigue syndrome (CFS) and

originated from the definition developed by Wessely *et al.*, (1998). The core components of the definitions stated above seem to highlight the key characteristics of fatigue as:

- i) Abnormal, excessive, subjective, unusual and persistent tiredness or exhaustion
- ii) Decreased muscle strength, feeling of lack of physical and mental energy
- iii) Impaired physical and cognitive functioning
- iv) The level of fatigue is disproportionate to the level of activity
- v) Fatigue interferes with daily activities and impairs quality of life.

Although the most frequently used term was ‘fatigue’, other terms such as ‘energy level’ (De Rooy *et al.* 2001), ‘tiredness’ (Garcia-Vega & Fernandez-Rodriguez 2004), ‘decline of vitality and vigour’ (Tanaka & Kazuma 2005) and ‘energy and vitality’ (Wolfe & Sirois 2008) were also used. However, none of these terms were defined, and none of the studies asked patients to describe the experience of fatigue in their own words. There is a considerable degree of overlap and repetition in the terminology used such as ‘reduced physical and mental energy’, ‘reduced vitality’, ‘feeling of tiredness’, ‘reduced energy level’ (not specified if mental or physical energy), ‘reduced muscle strength’ and ‘cognitive impairment’.

Analysis of the literature revealed that there is an absence of a universally accepted definition of IBD-fatigue and a lack of clarity in the terminology used to describe it. Some definitions focus on the symptom of fatigue, while others focus on its duration and severity. It is therefore, difficult to ascertain if the studies are measuring the same phenomenon. It is also unclear if ‘tired’, ‘fatigued’, ‘lack of energy’ or ‘lack of vitality and vigour’ all have the same meaning for both patients and health professionals, or if these terms can be used interchangeably.

2.4 Prevalence of IBD-fatigue

Prevalence of fatigue was previously reported as 41%-48% in remission and up to 86% in active disease (van Langenberg & Gibson 2010). The results were based on 254 patients derived from three studies; all recruited from specialist university clinics. Fatigue was measured as a secondary outcome to the main findings which related predominantly to disease activity, HRQoL or depression (Minderhoud *et al.* 2003, Bjornsson *et al.* 2004, Minderhoud *et al.* 2007). The reported prevalence may be confounded by a more severe and

complicated IBD presentation, and use of different scales to measure fatigue with no clear cut-off point to define the presence or absence of fatigue.

Since Van Langenberg & Gibson's (2010) review, fifteen papers were published reporting the prevalence of IBD-fatigue. The findings revealed that when disease is in remission, fatigue prevalence in UC patients varies from 22%-36% (Hauser *et al.* 2005, Romberg-Camps *et al.* 2010, Jelsness-Jørgensen *et al.* 2011b), and in CD patients from 27%-41% (Minderhoud *et al.* 2003, Hershfield 2005, Romberg-Camps *et al.* 2010, Graff *et al.* 2011, Jelsness-Jørgensen *et al.* 2011b). Fatigue prevalence was reported as 36% for CD patients in remission without irritable bowel syndrome (IBS)-like symptoms; however, it was much higher, at 60%, if CD patients also had IBS-like symptoms (Piche *et al.* 2010). In a population with mixed disease activity, fatigue prevalence was reported at 44%-64% (Lesage *et al.* 2011, Romkens *et al.* 2011, Tinsley *et al.* 2011, Bager *et al.* 2012). There are no data reported on fatigue prevalence for active UC; however, in active CD, fatigue was reported as 72%-86% (Minderhoud *et al.* 2007, Romberg-Camps *et al.* 2010, Graff *et al.* 2011).

Two studies compared the levels of fatigue between IBD and other chronic conditions (Bjornsson *et al.* 2004, Bol *et al.* 2010). Bjornsson *et al.* compared fatigue levels between primary sclerosing cholangitis (PSC), IBD and the general population; and Bol *et al.* explored fatigue levels and its specificity in MS and UC patients. Both studies reported similar levels of fatigue across the studied conditions, and Bol *et al.*, (2010) also drew a conclusion that fatigue in MS and UC has very similar characteristics.

The IBD-fatigue prevalence rates found in this review were similar to those previously reported (van Langenberg & Gibson 2010); however the data were derived from a total of 6,165 IBD patients, from sixteen different studies, with a variety of specialised university clinics and a community-based IBD register. This confirms that IBD-fatigue is highly prevalent across different settings, type and disease activity. These levels of IBD-fatigue are comparable with fatigue in other chronic conditions, e.g. 40%-89% in cancer (Jacobsen 2004, Lawrence *et al.* 2004, Stone & Minton 2008), 75%-78% in MS (Lerdal *et al.* 2007, Johansson *et al.* 2008, Leocani *et al.* 2008) and 41%-76% in rheumatoid arthritis (RA) patients (Hewlett *et al.* 2007, Parrish *et al.* 2008, Repping-Wuts *et al.* 2008). Despite the similarity of IBD-fatigue prevalence with other chronic conditions, it has not received the same amount of attention in research and clinical practice.

2.5 Types of fatigue and fatigue assessment scales

In the absence of qualitative data, the classification of types of fatigue in IBD was based on the assessment tools used to measure it. Some tools measured types of fatigue, while others measured types of functioning; however none of the scales were developed with an IBD-population. All tools used by reviewed papers are presented in the paper Czuber-Dochan *et al* (2013a) (Appendix II).

Five different scales measuring types of IBD-fatigue were used by 15 studies, with the Multidimensional Fatigue Inventory (MFI) (Smets *et al.* 1995) being the most frequently employed (n=8 studies) (Minderhoud *et al.* 2003, Minderhoud *et al.* 2007, Banovic *et al.* 2010, Bol *et al.* 2010, Romberg-Camps *et al.* 2010, Graff *et al.* 2011, Lesage *et al.* 2011, Bager *et al.* 2012). Four scales measuring type of functioning in IBD patients were used by 16 different studies. Some of the scales were symptom-specific such as the Fatigue Impact Scale (FIS) (Fisk *et al.* 1994), while others were generic health-related quality of life instruments e.g. Short-Form 36 (SF-36) (Ware & Sherbourne 1992, McHorney *et al.* 1993).

Studies referred to different types of fatigue; some were based on its severity (mild, moderate, substantial, severe), some on duration (chronic fatigue), and others on dimensions of fatigue (physical, mental, cognitive emotional, general, total). However, often the terms were neither defined nor explained. Due to lack of qualitative data collected from patients, it is impossible to confirm the different types of fatigue derived from the specific fatigue assessment tools.

The cut-off point for diagnosing fatigue has not been validated with patients and is left to the clinician's discretion. Two studies, despite using the same fatigue assessment tool (MFI), adopted different cut-off points to diagnose fatigue; Romberg-Camps *et al.*, (2010) used a cut-off greater than 14 points, while Minderhoud *et al.*, (2003) used a cut-off greater than 13 points. In the absence of any patient data on fatigue impact, it is difficult to say if and how much difference one point makes to the individual affected by fatigue. Inconsistency was also evident in diagnosing chronic fatigue. Some studies reported fatigue as 'chronic' if the duration of the symptom was longer than one month (Romkens *et al.* 2011), while others made this diagnosis after 6 months (Jelsness-Jørgensen *et al.* 2012a).

Currently, there are no guidelines on how to measure IBD-fatigue in clinical practice and which tool(s) to use. All were developed as a research rather than a clinical tool, to measure fatigue in chronic conditions other than IBD, and all, except Functional Assessment of

Chronic Illness Therapy-Fatigue Scale (FACIT-F) (Tinsley *et al.* 2011), have not been validated with IBD patients. Of the tools used by the reviewed studies to measure IBD-fatigue, only IBDQ was developed with an IBD population; however IBDQ is a tool to measure quality of life rather than fatigue, and has only one question on fatigue and one on level of energy (Irvine 1993, Irvine 1999). This may have further impact on validity and specificity of the scales available to measure fatigue in the IBD population. Most of the reviewed studies described the fatigue scales used, but did not provide a rationale for selecting the specific tool. It is not known how different or similar fatigue is amongst people with IBD, how it differs between different severity (e.g. mild, moderate, severe) points, and how it compares to fatigue in other chronic conditions. This information is required before deciding if fatigue assessment tools can be used across different disease populations.

2.6 Factors associated with fatigue

The mechanism of IBD-fatigue is not well understood (Minderhoud *et al.* 2003); though it may be linked to the inflammatory process caused by immune system dysregulation, anaemia and medication (Casati *et al.* 2000, Loftus *et al.* 2008, Bol *et al.* 2010). The reviewed literature revealed different groups of factors, such as physical, psychological and situational, and their relationship to the development and severity of fatigue in IBD. The list of factors within each category, the size and the direction of the relationship are presented in Appendix II, and a summary is provided below.

2.6.1 Physical factors

Numerous physical factors were found to be associated with IBD-fatigue. The relationship between fatigue and other variables such as duration of illness (Tanaka & Kazuma 2005, Bol *et al.* 2010, Jelsness-Jørgensen *et al.* 2011b), anaemia (Minderhoud *et al.* 2003, Simren *et al.* 2008, Romberg-Camps *et al.* 2010, Graff *et al.* 2011, Jelsness-Jørgensen *et al.* 2011b, Bager *et al.* 2012), pain (Bjornsson *et al.* 2004, Kalaitzakis *et al.* 2008), sleep pattern (Simren *et al.* 2008, Wolfe & Sirois 2008, Banovic *et al.* 2010, Graff *et al.* 2011, Jelsness-Jørgensen *et al.* 2011b), age and gender (Hauser *et al.* 2004, Simren *et al.* 2008, Romberg-Camps *et al.* 2010) are however not well understood, with conflicting results being reported.

Disease activity was one of the factors with the most consistent positive correlation (p value ranging from 0.05 - 0.0001) to the presence and severity of fatigue, reported by ten studies (Bjornsson *et al.* 2004, Hauser *et al.* 2005, Minderhoud *et al.* 2007, Simren *et al.* 2008, Bol *et al.* 2010, Piche *et al.* 2010, Graff *et al.* 2011, Tinsley *et al.* 2011, Jelsness-Jørgensen *et al.* 2011b, Bager *et al.* 2012). Nevertheless, other studies reported fatigue when IBD was in remission ((Minderhoud *et al.* 2003, Bjornsson *et al.* 2004, Banovic *et al.* 2010).

Some of the medications used to treat IBD, such as immunomodulators (methotrexate) and thiopurines (azathioprine), were reported to be associated with greater fatigue severity (p=0.024) (Jelsness-Jørgensen *et al.* 2011b), but there was no significant difference observed in relation to other groups of medication frequently used to treat IBD, such as anti-tumour necrosis factor alpha (anti-TNF α), 5-aminosalicylates, and steroids (prednisolone) (Lee *et al.* 2009, Romberg-Camps *et al.* 2010, Jelsness-Jørgensen *et al.* 2011b). More information regarding medical treatment of IBD is provided in Chapter 3.

Demographic factors, age and gender, though frequently measured, were not found to be associated with fatigue, except by one study (Bager *et al.* 2012) where older women with UC reported more severe fatigue (p<0.05), and two studies (Simren *et al.* 2008, Romberg-Camps *et al.* 2010) identified female gender as being significantly associated (p=0.0001 and p<0.05 respectively) with fatigue.

Poor sleep quality, and altered sleep pattern and duration were reported as significant factors (p=0.001) by four studies (Simren *et al.* 2008, Wolfe & Sirois 2008, Graff *et al.* 2011, Jelsness-Jørgensen *et al.* 2011a); however Banovic *et al.*'s (2010) results did not confirm these findings (p=0.11).

In the medical literature, anaemia is presented as the most prevalent complication in IBD, affecting 16% of outpatients and 68% of hospitalised patients (Gasche *et al.* 2004, Stein *et al.* 2010), and is reported as the most common cause of fatigue. In the reviewed literature anaemia was reported as a significant factor associated with fatigue (p value ranged from 0.0001 – 0.05) by three studies (Simren *et al.* 2008, Jelsness-Jørgensen *et al.* 2011a, Jelsness-Jørgensen *et al.* 2011b). Two studies reported contradictory results; Romberg-Camps *et al.*, (2010) identified a positive correlation between anaemia and fatigue (p<0.05) only with UC patients, while Bager *et al.*, (2012) reported a significant relationship (p<0.05) only with male CD patients. One study identified no significant correlation (p value not stated) between these two factors (Minderhoud *et al.* 2003).

Iron deficiency is the most common cause of anaemia and should be tested regularly (Kulnigg & Gasche 2006). Assessment of iron status in IBD patients using common biochemical values alone has been reported to be insufficient (Gasche *et al.* 2004, Gasche 2007, Gisbert & Gomollon 2008) and more specific tests, e.g. ferritin level, transferrin receptor ratio and others, are recommended to diagnose and treat anaemia (Bodemar *et al.* 2004, Stein *et al.* 2010).

Better general health demonstrated significant negative correlation with fatigue ($p=0.001$) (Bjornsson *et al.* 2004, Tinsley *et al.* 2011, Jelsness-Jørgensen *et al.* 2011b). Being newly diagnosed (Tanaka & Kazuma 2005, Bol *et al.* 2010), having pain (Bjornsson *et al.* 2004) and other co-morbidities were reported as contributors to more severe fatigue (p value 0.01 - 0.05) by some studies, but these factors were not found significant (p value not stated) in other studies (Kalaitzakis *et al.* 2008, Jelsness-Jørgensen *et al.* 2011a).

The conflicting results for assessed factors and their relationship to fatigue may be explained by the heterogeneity of the sample, different population sizes, and different clinical and statistical tests being used by different studies.

The presence of multiple symptoms, also called symptom clusters and defined as an occurrence of ‘two or more concurrent symptoms that are related to each other’ (Kim *et al.* 2005:278), e.g. fatigue, pain, diarrhoea, bowel urgency, sleep disturbance, anxiety, stress, are frequently reported in IBD, both in active and quiescent disease. Presence of different symptoms and different symptom clusters, both physical and psychological and their relationship to fatigue in IBD is not well understood. It is possible that participants with multiple symptoms will also be affected by more severe fatigue; however, the impact of symptom clusters on fatigue has not been studied. In a condition related to the digestive system, such as IBD, it is notable that nutritional factors and the impact of diet on fatigue have not been studied.

2.6.2 Psychological factors

Psychological factors such as anxiety (Kalaitzakis *et al.* 2008), depression (Bjornsson *et al.* 2004, Hauser *et al.* 2005, Kalaitzakis *et al.* 2008, Banovic *et al.* 2010, Bol *et al.* 2010), HRQoL (Minderhoud *et al.* 2003, Kalaitzakis *et al.* 2008, Jelsness-Jørgensen *et al.* 2011b), stress and emotive coping (Tanaka & Kazuma 2005, Bol *et al.* 2010, Graff *et al.* 2011, Jelsness-Jørgensen *et al.* 2012a), were all associated with fatigue. Depression was consistently associated with fatigue across all of these studies (p value 0.001 - 0.013), with

the exception of Banovic *et al.*, (2010). There was a positive association between depression and fatigue; however the direction of the relationship was not clear. It was difficult to ascertain if depression was the cause, or the outcome of fatigue, or whether one simply co-exists with the other.

Not all studies measured the same factors and different effect sizes were reported, making a comparison across the studies impossible. The poorly understood cause-effect relationship between various factors and fatigue severity further contributes to its inadequate understanding.

2.6.3 Situational factors

Situational factors such as unemployment ($p=0.05$), financial difficulties ($p=0.0001$) (De Rooy *et al.* 2001, Simren *et al.* 2008, Jelsness-Jørgensen *et al.* 2012a), social support ($p=0.05$) (Tanaka & Kazuma 2005), role limitation ($p=0.004$) (Hauser *et al.* 2005) and people's perception of not achieving full potential ($p=0.05$) (De Rooy *et al.* 2001, Jelsness-Jørgensen *et al.* 2012a) were all associated with fatigue severity, however level of education (Simren *et al.* 2008, Jelsness-Jørgensen *et al.* 2012a), relationship status and living alone (Simren *et al.* 2008) were not. It has been shown that people with a better support system ($p<0.05$) (Tanaka & Kazuma 2005), and those who have a perception of achieving their full potential ($p<0.05$) (De Rooy *et al.* 2001, Jelsness-Jørgensen *et al.* 2012a), report lower levels of fatigue. It was not clear if the support related to physical activities such as shopping, cooking, cleaning, driving, or more psychological and emotional types of support, and whether achieving full potential related to professional or personal aspects of life.

2.7 Ways of managing fatigue

The reviewed literature reported five randomised controlled trials (RCTs); two testing non-pharmacological (Garcia-Vega & Fernandez-Rodriguez 2004, Vogelaar *et al.* 2011) and three pharmacological (Lichtenstein *et al.* 2002, Minderhoud *et al.* 2007, Loftus *et al.* 2008) interventions for managing IBD, where fatigue was measured either as a primary or secondary outcome. Since the publication of the review (Czuber-Dochan *et al.* 2013a), further intervention studies were published and these are included in the discussion chapter.

2.7.1 Non-pharmacological management

Two RCT pilot studies evaluated non-pharmacological interventions for managing IBD, and fatigue was measured as a secondary outcome. Garcia-Vega & Fernandez-Rodriguez (2004) tested whether stress management decreases disease activity in CD patients. The study compared professionally-led (same psychologist) stress management, with a self-directed stress management (patients were given written guidelines and an audiotape to practice regular home relaxation) programme, or conventional medical treatment for CD. CD patients (n=45), were randomly allocated to three equal sized (n=15) treatment groups delivered over 8 weeks, with outcome measures after treatment, and at 6 and 12 months. Patients kept a daily symptom diary and recorded the presence or absence of up to 10 most common symptoms (a list of the symptoms was not provided in the paper) in CD including fatigue, and rated the severity on a three point scale: 1=mild, 2= moderate and 3=severe. Only the self-directed stress management group reported a small, but not statistically significant ($p<0.10$), reduction of fatigue after treatment and at 6 and 12 months follow-up (Garcia-Vega & Fernandez-Rodriguez 2004).

The RCT conducted by Vogelaar and colleagues (2011) tested the feasibility of psychological interventions for fatigue management. Fatigue was assessed by use of the Checklist Individual Strength (CIS) (Vercoulen *et al.* 1994). They compared problem-solving therapy (10 sessions over three months, 10 participants), solution-focused therapy (five sessions over three months, (10 participants) and usual treatment (20 participants). Usual treatment was referred to as ‘standard medical care’, but it is unclear if the standard care referred to CD or fatigue management. Due to high attrition across all three groups, the data were analysed for only seven patients in the solution-focused therapy, five patients in the problem-solving therapy and 11 patients in the control group. Six patients in the solution-focused therapy group and three patients in the problem-solving therapy reported a slight, but not significant reduction of fatigue (p value not reported) from baseline to three months follow up. The high attrition rate may suggest that the interventions were not well accepted by the study participants.

Both studies produced no evidence of effectiveness of the tested interventions. This may be attributed to the short intervention period, a lack of clarity of what each intervention entailed (what was the active ingredient of the intervention), and the small sample size, insufficient to detect a difference. Therefore, none of the tested interventions seem promising for managing fatigue.

2.7.2 Pharmacological management

Two RCTs examined the effect of infliximab as treatment for patients with active CD (Lichtenstein *et al.* 2002, Minderhoud *et al.* 2007) and one evaluated the effects of adalimumab maintenance therapy in patients with moderate to severe CD (Loftus *et al.* 2008). In all three studies HRQoL was measured as a primary and fatigue as a secondary outcome.

In the RCT by Lichtenstein *et al.*, (2002) participants with CD (n=83) were randomised to one of four arms: placebo, a single dose of infliximab of 5 mg/kg, a single dose of infliximab of 10 mg/kg, or a single dose of infliximab of 20 mg/kg. A significantly larger proportion of infliximab patients in comparison to the placebo group reported having full or a lot of energy ($p=0.013$), with no or hardly any difficulty doing sport or leisure activities ($p=0.011$), and being very satisfied with their personal life ($p=0.046$). They also reported significant improvements regarding fatigue ($p=0.038$). Patients' outcomes were measured at 2, 4, 8 and 12 weeks from the initial treatment, with the IBDQ (Irvine 1993, Irvine 1995). Correlations between IBDQ and clinical parameters were calculated using the Spearman correlation coefficient, which enables calculation of the relationship between two variables (Bland 1987). No relationship was found between the infliximab dose and the proportion of patients responding to the CD treatment.

The second RCT (Minderhoud *et al.* 2007) examined the effect of infliximab on fatigue in CD patients. Fourteen patients took part and all received placebo at baseline, followed by 5mg/kg infliximab at two weeks. Fatigue scores on the MFI (Smets *et al.* 1995) were significantly lower ($p<0.05$), after both placebo and infliximab infusion compared to the baseline. The authors used McNemar's test for matched samples and the Wilcoxon matched-pairs test (tests specific for small sample size) and conclude that fatigue reduction is subject to a placebo effect (Minderhoud *et al.* 2007); however the placebo has a short term effect. The effect of infliximab on IBD-fatigue was reported as inducing a longer lasting effect, though this conclusion should be treated with caution on the grounds of the small sample size (n=14), lack of control group and selective reporting of study results.

In a third study (Loftus *et al.* 2008) CD patients who positively responded to adalimumab treatment (n=492) were randomised into three treatment arms: adalimumab at induction only, 40 mg adalimumab every week and 40 mg adalimumab every other week for 12 weeks, and were followed up for 56 weeks. The differences between the three groups and

the different follow-up time points were calculated using ANCOVA test, which is a correct test for calculating effect size between two or more independent groups (Marston 2010). All three groups reported a significant reduction of fatigue after the induction injection of adalimumab ($p < 0.0001$). From week 12 onwards the induction-only arm reported worsening of fatigue at the subsequent visits. The weekly adalimumab group and the every other week group reported significant improvements of fatigue at week 12, 26 and 56, $p < 0.05$ and $p < 0.001$ respectively. There was no significant difference between the adalimumab every week and every other week arm except at week 12.

Infliximab and adalimumab are anti-TNF α medications, used to treat severe CD and may also be used to treat moderate to severe UC, rather than fatigue (Mowat *et al.* 2011), and they currently account for 64% and 31% of medical treatment cost in CD and UC respectively (van der Valk *et al.* 2014). All three studies only included patients with CD; therefore it is unknown if the medications would bring the same positive effect on fatigue for patients with UC. Additionally, the adverse effects such as increased risk of serious infection and malignancy (Bongartz *et al.* 2006, Stallmach *et al.* 2010) combined with high cost of the medication, would probably preclude it from being prescribed for treating fatigue as a primary indication in the absence of active inflammation.

2.8 Impact of fatigue on an individual's life

Fatigue has been reported to be one of the most debilitating and troublesome symptoms of IBD. It affects every aspect of an individual's life and has a detrimental effect on HRQoL (Casati *et al.* 2000, De Rooy *et al.* 2001, Minderhoud *et al.* 2003, Kalaitzakis *et al.* 2008, Jelsness-Jørgensen *et al.* 2011a). Depending on the assessment scale used, different areas of functioning, such as physical, cognitive, psychological, emotional and social, have been presented in the literature. The frequently used scales to measure functioning affected by fatigue were SF-36 (generic QoL scale - used by five studies), FIS (fatigue specific impact scale - used by four studies) and IBDQ (a scale developed to measure QoL in IBD - used by four studies). The impact of using generic or fatigue specific scales to assess the impact of fatigue was not discussed in the literature. All the studies reporting fatigue impact were of quantitative design; therefore there was no contextual data reporting the extent of the impact on a person's life.

Since many people are diagnosed with IBD at a young age, the impact of fatigue on their education, personal and professional lives may be even greater in IBD than in other chronic conditions (Lesage *et al.* 2011, Jelsness-Jørgensen *et al.* 2011b). Little is known about how IBD-fatigue is experienced and managed in everyday adult life (Tanaka & Kazuma 2005). However, a study with children and adolescents reported that fatigue may in the longer term limit their ability to work or to study, demonstrating that 60% of children with CD experienced significant school absenteeism (Moody *et al.* 1999). Of those who had taken examinations, 80% believed they had underachieved. Academic achievement in youth impacts on life chances and potential in adulthood (Mayberry *et al.* 1992, Moody *et al.* 1999, Bajorek *et al.* 2015). Other studies of children and adolescents with IBD in remission have demonstrated a negative correlation between fatigue and HRQoL (Nicholas *et al.* 2007, Marcus *et al.* 2009), however no studies were identified that have reported on the experience of fatigue in adults with IBD. The impact and long-term consequences of fatigue in IBD have not been studied. It is therefore important to study cumulative effects of fatigue on individuals with IBD. Such information would allow a better understanding of fatigue and would provide a foundation for patient assessment, development and testing of interventions for better symptom management.

Often patients' concerns are not well understood by others, such as HCPs as well as family and friends. This has been highlighted by a study comparing IBD patients' concerns and feelings with the perceptions of their close family relations and physicians. Fatigue has been reported as a daily concern by 66% of patients, but only 36% of physicians and 44% of close family relations were in agreement with the patient's perception of their fatigue level and the effort needed to maintain their daily activities (Lesage *et al.* 2011). This lack of understanding by relatives and clinicians may result in patients feeling misunderstood and isolated, and therefore not reporting the symptom. The majority of studies prior to the present study on IBD-fatigue were quantitative in design and aimed to assess the effectiveness of pharmacological treatment or to identify determinants of fatigue and their correlation to HRQoL; fatigue was often measured as a secondary outcome. There was little qualitative evidence on how fatigue is experienced and reported by people diagnosed with IBD and how it impacts on individuals' lives (Czuber-Dochan *et al.* 2013a).

2.9 Summary

Almost half of the reviewed papers were published in the 3-year period since van Langerberg & Gibson (2010), indicating an increased interest in IBD-fatigue. Papers published since Czuber-Dochan *et al* (2013a) are included in the Discussion chapter.

The literature review confirmed that fatigue is highly prevalent, even when IBD is in remission and is more prevalent than in the general population. The term ‘fatigue’ has many different uses and definitions, with no single definition being commonly accepted. This broad spectrum of uses only adds to the difficulty of understanding fatigue as a symptom of IBD. This may also explain the reasons for IBD-fatigue being neglected in research and clinical practice.

In the majority of studies, fatigue was measured as a secondary outcome, rather than the primary focus of the investigation. This results in only superficial exploration of the phenomenon of fatigue and consequent inadequate understanding. There is evidence of various factors contributing to IBD-fatigue and its severity. However, the research is mostly descriptive and of moderate to low quality (Czuber-Dochan *et al.* 2013a). There is a lack of consistency between the various factors measured across different studies. The mostly small studies, insufficient description of the fatigue assessment scales, and use of instruments not tested in an IBD population, may have an impact on the results’ validity and reliability (Polit & Beck 2006). The factors most frequently measured by different studies are age, gender and disease activity, but only disease activity is consistently associated with greater levels of fatigue. It is commonly known that patients with active disease and high inflammatory markers also experience a higher level of fatigue (Cohen & Hanauer 1995, Cho *et al.* 2009, Dantzer 2009), but this cannot be explained by disease activity alone as a high prevalence of fatigue in remission has been reported by several studies.

All but one of the papers were quantitative in nature. The qualitative data came from one, a mainly quantitative, study which aimed to identify how IBD affected an individual’s daily life (Wolfe & Sirois 2008), and therefore information relating to IBD-fatigue was limited. The first ever qualitative study designed specifically to explore the experience of fatigue in people with IBD (Czuber-Dochan *et al.* 2013b), was published by the PhD researcher after the published review. The study identified that fatigue had far reaching, negative consequences on every aspect of an individual’s life, restricting and limiting their roles and

functions. Although the study employed focus group interviews, each participant had a limited opportunity to describe their experience in detail.

This literature review conducted at the time of the present research confirmed a major gap in the literature on IBD-fatigue from the patient perspective. The focus group study confirmed the need for further research to better understand fatigue as experienced by people with IBD, and how fatigue impacts on their lives. An in-depth qualitative study will provide information from the patients' point of view about the experience of fatigue.

Chapter 3 Inflammatory bowel disease

3.1 Introduction

Inflammatory bowel disease (IBD) is a generic term for an idiopathic and complex disorder of the gastrointestinal tract with wide variation in clinical presentation (Nikolaus & Schreiber 2007, Clara *et al.* 2009). The two major forms of IBD are Crohn's disease (CD) and ulcerative colitis (UC) (Thia *et al.* 2011). At times unspecific symptoms and limited test accuracies may delay IBD diagnosis, or patients may be diagnosed with indeterminate colitis (Vavricka *et al.* 2012). In CD inflammation affects the entire digestive tract, while in UC only the large intestine is affected (Nikolaus & Schreiber 2007). IBD is lifelong, chronic, unpredictable, relapsing and remitting inflammatory condition, and whilst it does not generally affect mortality it does contribute to long-term morbidity, increased risk of developing colorectal cancer and reduced quality of life (QoL) (Lix *et al.* 2008, Floyd *et al.* 2015).

This chapter presents background information on IBD and aims to:

- Provide an overview of IBD against which IBD-fatigue can be viewed
- Outline the clinical presentation of IBD, its symptoms and diagnostic tests
- Briefly present medical and surgical treatment options
- Discuss the impact of IBD.

Currently there is no known cure for IBD. People diagnosed with IBD require life-long medical treatment to induce and maintain remission, and they live with a constant worry of another relapse (Costa *et al.* 2005, Pithadia & Jain 2011, Goodhand *et al.* 2013). During relapse, patients often require hospitalisation with intensive medical or surgical treatment. There is a high rate of hospitalisation for people with IBD (85%) which is often repeated (European Federation of Crohn's and Colitis Association 2012).

The total medical cost of IBD to the National Health Service (NHS) is comparable to that of other major chronic conditions (e.g. cancer and diabetes mellitus), and is calculated to be about £900 million per annum, with an average annual cost of £3,000 per patient (Bassi *et al.* 2004, Cummings *et al.* 2008). However, this cost does not include the wider personal and emotional impact or economic cost for each individual. Despite being one

of the most common chronic gastrointestinal conditions and causes of morbidity in the UK, IBD has not been included in the National Service Framework programme (Department of Health 2011). This suggests that the condition does not receive adequate NHS and government attention.

The IBD Standard Working Group (2009, 2013) recommends that care for people with IBD should be patient-centred and responsive to individual needs and should offer choice in terms of clinical care and management. However, the evidence shows significant discrepancies between patients' expectations of holistic management and clinicians' predominant emphasis on control of inflammation (Dudley-Brown & Baker 2012). *'The national audit of inflammatory bowel disease service provision in adults'* (Royal College of Physicians 2014) revealed large disparity in service and organisation of IBD care in the UK; only 27% of hospitals report a full core IBD team, and only 74% of patients who relapse are seen within 7 days as advocated by IBD Standards (2013). IBD patients receive varying quality care due to inconsistent service provision: 37% receive IBD specialist nurse support, 67% specialist dietitian input, 48% of services provide regular education opportunities for patients and only 12% of services report access to a clinical psychologist (The Inflammatory Bowel Disease Standards Group 2013). These variations in terms of services and standard of care inevitably leave many patients with undiagnosed and unmet needs in relation to their physical and psychological needs, including fatigue.

3.2 Prevalence and aetiology of IBD

IBD has long been considered a disease predominantly affecting a Western population with the highest incidence rates and prevalence for both CD and UC reported in northern Europe (2.2 million) and the United States of America (USA) (1.4 million) (Loftus 2004, Goh & Xiao 2009). It is estimated that IBD affects over 300,000 people in the UK, equating to one in 250 adults (Rubin *et al.* 2000, Molodecky *et al.* 2012, The Inflammatory Bowel Disease Standards Group 2013). The prevalence of UC is approximately 150 per 100,000 and CD affects around 100 per 100,000 population (Rubin *et al.* 2000, Rampton & Shanahan 2006). The incidence of IBD is rising in developing countries, such as southern Europe and Asia, as they adopt a more westernised style of life (Goh & Xiao 2009, Mowat *et al.* 2011).

The aetiology of IBD is not completely understood. The current leading hypotheses emphasise the aggregate effect of genetic and environmental factors that may predispose an individual to dysregulation of the gastrointestinal immune system (Korzenik & Podolsky 2006, Xavier & Podolski 2007). It seems that genes play a significant part in the development of the disease, interacting with environmental triggers that lead to an abnormal immunological reaction to normal gut bacteria (Hart & Kamm 2002, Hart *et al.* 2004, Baumgart & Carding 2007, Ng *et al.* 2009). Although IBD is more prevalent in Caucasian populations, ethnic and racial factors seem to have lesser influence in migrants who settle in high prevalence areas. This would support environmental hypotheses for IBD development (Loftus 2004, Rampton & Shanahan 2006). Genetic factors appear to be more important in CD than in UC with increased risk of developing the condition in first-degree relatives (Rampton & Shanahan 2006).

Ethnic differences are reported to be narrowing, with incidence of IBD in African-Americans approaching that of Caucasian populations (Binder 2004, Loftus 2004). The risk of IBD among African-Caribbean children living in the UK is reported to be similar to that of white children (Sawczenko *et al.* 2001). There is also evidence that immigrants from South Asia who have moved to the UK and their offspring, are at the risk of developing UC comparable with the white indigenous British population (Montgomery *et al.* 1999, Goh & Xiao 2009). This would indicate that a westernised way of living and environmental factors play an important role in the development of IBD, although possibly only in those with a genetic predisposition (Annese *et al.* 2007). Differences in incidence across age, time, and geographic regions suggest that environmental factors significantly modify the expression of CD and UC (Cornish *et al.* 2008, Gearry *et al.* 2010).

The onset of IBD may occur at any age, but the most common is in adolescents and early adulthood (16 – 29 old) (Carter *et al.* 2004). The second peak incidence is in the 50s and 60s age groups, with both genders being almost equally affected by CD and UC (Loftus 2004, Mowat *et al.* 2011). Men are significantly more likely than women to be diagnosed in their 50's and 60's (Loftus 2004).

A number of modifying factors have been identified that increase the risk of the disease, of which the strongest include family history of IBD, cigarette smoking, excessive childhood hygiene, appendectomy, anti-inflammatory medication, antibiotics and oral contraception (Gearry *et al.* 2010). Other factors such as diet, perinatal and childhood factors, measles and mycobacterial infection have also been proposed as influencing the

onset of IBD; however, the mechanism of this association remains unclear (Fiocchi 1998, Loftus 2004). Smoking is probably the strongest environmental risk factor for the development of CD, and smoking cessation significantly (65%) reduces the risk of relapse; conversely, smoking appears to be protective for UC, which tends to be associated with non-smokers or ex-smokers (Johnson *et al.* 2005).

3.3 Signs, symptoms and diagnostic tests

A diagnosis of IBD is based on clinical, biochemical and pathological features. The most common presenting symptoms in both CD and UC include frequent, urgent and profuse diarrhoea, often with blood and mucous, with accompanying abdominal pain, loss of appetite, weight loss, malnutrition and profound fatigue (Rampton & Shanahan 2006, Norton 2008, Targan *et al.* 2003).

In UC inflammation and ulceration may be distal or more extensive. In distal disease the inflammation is confined only to the rectum (proctitis) and in more extensive disease it includes left-sided colitis or may involve the entire colon (pancolitis) (Carter *et al.* 2004). Inflammation is limited primarily to the mucosa and consists of continuous involvement of variable severity with ulceration, oedema, and haemorrhage (Hendrickson *et al.* 2002, Satsangi *et al.* 2006). Toxic mega colon (dilation of the colon) can be a feature of severe colitis, and can be potentially life-threatening (D'Haens *et al.* 2007). The rectum is involved in 95% of patients. UC can be cured by total resection of the rectum and the colon, although extraintestinal manifestations (e.g. iritis, arthropathy, primary sclerosing cholangitis) will remain.

CD most commonly affects the ileocecal region and the terminal ileum, but it may involve any part of the digestive tract from mouth to anus (Hendrickson *et al.* 2002, Satsangi *et al.* 2006). Inflammation can be transmural, penetrating the entire depth of the intestinal wall, often extending to the serous membrane, and the affected segments are separated by intervening normal bowel (skip lesions). This may result in a sinus tract, fistula formation, fissuring ulcers or thickening of small bowel folds (Rampton & Shanahan 2006, Tozer *et al.* 2009). Stricturing and narrowing of the intestine can result in problems with digestion and obstructive symptoms causing severe abdominal pain, requiring surgery.

Presenting gastrointestinal features of IBD can be worsened by frequent extraintestinal immune-related complications principally involving the joints, skin, eyes, liver and kidneys (Danese *et al.* 2005, Kethu 2006). Extraintestinal manifestations are usually related to intestinal disease activity and may precede or develop concurrently with intestinal symptoms and are similar in both conditions. Approximately 50%-60% of patients with IBD are affected by extraintestinal manifestation and about 25% report more than one (Baumgart & Sandborn 2007, Nikolaus & Schreiber 2007). Some of the extraintestinal symptoms, e.g. arthritis and primary sclerosing cholangitis, are also accompanied by fatigue and abdominal pain (Danese *et al.* 2005). If CD is diagnosed in childhood, delays in growth and sexual maturation are often observed (Hendrickson *et al.* 2002, Sawczenko & Sandhu 2003).

While UC and CD have many similarities in their clinical presentation, they also have differences. The most consistent intestinal feature of UC is the presence of blood and mucus mixed with stool, diarrhoea, and low abdominal cramping which intensifies during the passage of bowel movements. UC is usually diagnosed earlier after the onset of symptoms than CD due to the visible presence of blood in the stools which alerts patients to seek help (Hendrickson *et al.* 2002). The diagnosis of CD may be delayed by its more subtle presentation, as the most frequent symptoms include pain, diarrhoea, nausea or dysphagia (Knoblauch *et al.* 2002, Vavricka *et al.* 2012, Schoepfer *et al.* 2013). Due to pain after eating, patients with gastro-duodenal CD often restrict their diet intake to reduce the discomfort (Hendrickson *et al.* 2002, Carter *et al.* 2004). In CD with extensive small bowel disease severe pain, anorexia, diarrhoea, and weight loss may often be present (Mishkin 1997, Nguyen *et al.* 2008). Colonic CD may mimic UC, presenting with diarrhoea with blood and mucous associated with cramps, lower abdominal pain that is often relieved by defecation (Hendrickson *et al.* 2002, Satsangi *et al.* 2006). Perianal disease is common in CD, as are anal tags, deep anal fissures and fistulae. CD is associated with a 54%-78% rate of relapse within the first 18 - 24 months following the initial diagnosis (Carter *et al.* 2004).

Diagnosis of IBD is generally based on symptom history and presenting clinical features, combined with clinical tests (e.g. endoscopic, radiological), histological findings and blood tests including raised inflammatory markers such as C-reactive protein and erythrocyte sedimentation rate (Shen & Lashner 2006, Norton *et al.* 2008, Card *et al.* 2014). In the mild presentation, both UC and CD can be mistaken for irritable bowel

syndrome leading to delayed diagnosis (Vavricka *et al.* 2012, Schoepfer *et al.* 2013). Stool culture, including *Clostridium difficile* toxin, is essential to exclude infection.

3.4 Treatment options for IBD

The ultimate treatment goal for IBD patients is amelioration of active disease episodes to achieve mucosal healing, maintenance of clinical remission and maximise QoL (Mowat *et al.* 2011). The treatment options are generally based on a combination of drugs, diet and surgery, and largely depend on diagnosis, disease site and severity. Patients should be involved in treatment decision-making to improve compliance with the treatment plan (The Inflammatory Bowel Disease Standards Group 2013).

3.4.1 Medical management

The focus of medical treatment in IBD is on managing acute episodes, induction and maintenance of remission, relapse and complications prevention. The majority of patients require long-term or permanent medical treatment, with only about 6% not taking any medication (European Federation of Crohn's and Colitis Association 2012). The main four groups of medications for IBD and the proportion of taking these drugs at any one time are: aminosalicylates (47%), corticosteroids (21%), biological drugs (27%), and immunosuppressants (33%) (European Federation of Crohn's and Colitis Association 2012). Antibiotics also play an important role to treat secondary complications, such as an abscess or infection (Mowat *et al.* 2011).

The choice of drug treatment is dictated by the type (UC or CD), severity of the disease, and patient's susceptibility to medication. Often combination therapy from two groups is more effective than monotherapy to induce and maintain remission (Ansari *et al.* 2002, Marteau *et al.* 2005, Mowat *et al.* 2011). Compliance with treatment is an important factor in optimising treatment and controlling the disease (Greveson 2008, Horne *et al.* 2009).

Medical treatment can be introduced in a 'step-up' or 'top-down' approach, with both of these approaches creating different risks for the patient (Hanauer 2009, Lichtenstein *et al.* 2009). In a 'step-up' approach, bringing the inflammation under control and establishing remission may take longer, adding to prolonged physical discomfort and complications, and psychological stress (Hanauer 2009). A 'top-down' approach, on the other hand,

might be more effective and prevent much of the tissue destruction, but at the same time it may expose patients to unnecessary risks (exposure to highly toxic drugs) and side effects of medication (Hanauer 2009, D'Haens 2010, van der Have *et al.* 2014).

Balancing the therapeutic benefits of medications against the side effects of corticosteroids (such as weight gain, moon-face, acne, mood swings, dyspepsia, diabetes, septic complications, increased risk of osteoporosis), biologics and immunosuppressive treatment (nausea, vomiting, flu-like illness, bone marrow suppression, increased risk of lymphoma and hepatitis) requires regular blood count tests, renal and liver function monitoring (Compston 2003, Carter *et al.* 2004, de Vries *et al.* 2009).

Uncertainties related to the effectiveness of medication, the regime of intravenous administration of medication requiring day-care hospitalisation, side effects, and monitoring of the risk of cancer may additionally contribute to the severity of fatigue (Jess *et al.* 2007, Tremaine *et al.* 2007, Toruner *et al.* 2008).

3.4.2 Surgical management

Depending on the disease trajectory, severity and complications, between 70 - 80% of all IBD patients require surgery at some time in their life (Clark 2011, The Inflammatory Bowel Disease Standards Group 2013). UC patients not responding to medical therapy, with poorly controlled disease or with dysplasia may require surgery (Carter *et al.* 2012). The most frequently performed surgical procedures in UC are total proctocolectomy with ileal J-pouch-anal anastomosis (construction of an internal ileo-anal pouch) or proctocolectomy with temporary or permanent ileostomy formation (Huetting *et al.* 2005). Approximately 25 - 40% of patients with severe UC will require sub-total or total colectomy (removal of the affected area or the entire colon). In the case of medically refractory UC, total colectomy provides the only permanent cure for gastrointestinal symptoms, but not for extraintestinal complications (Travis 2004). Those with a pouch may develop debilitating pouchitis leading to urgency, frequency and faecal incontinence (Huetting *et al.* 2005).

Despite a generally conservative approach to CD treatment, approximately 20 - 24% of patients require surgery within 3 years, and nearly 80% within 20 years of disease onset (Silverstein *et al.* 1999, Sands *et al.* 2003). In patients with CD, due to poor healing and progressive disease, surgery is recommended only if they do not respond to medical treatment or have complications such as a perforation, abscess, haemorrhage, strictures

or complete bowel obstruction (Larson & Pemberton 2004). Surgical management of CD involves limited resection of the most diseased intestine and management of sepsis, i.e. drainage of abscesses and fistulae.

CD and UC are the most common reasons for ileostomy, however stoma formation surgery has been reported to have a negative impact on physical, psychological and social functioning of the individual (Brown & Randle 2005). Physical aspects of stoma functioning, body image, sexual attractiveness and QoL were frequently reported concerns requiring psychological adjustment, but at the same time having a stoma increased patients' perceived control of their lives (Brown & Randle 2005, Simmons *et al.* 2007). Strong interpersonal relationships and support from healthcare professionals can help patients to improve their acceptance of IBD and adjustment to living with stoma, dispelling negative thoughts and improving QoL (Simmons *et al.* 2007, Aronovitch *et al.* 2010).

3.4.3 Nutritional support and dietary therapy

Decreased appetite and increased energy expenditure put many IBD patients at high risk (80%) of weight loss (Valentini *et al.* 2008), and many (85%) develop nutritional deficiencies and malnutrition (Gassull & Cabré 2001, Nguyen *et al.* 2008). This is partially due to the underlying intestinal inflammation and malabsorption, and partially as an effect of reduced dietary intake or avoidance of specific foods perceived to be contributing to symptom severity (Razack & Seidner 2007). Patients should receive dietary advice and their nutritional assessment should be performed regularly by a dietitian with special interest in gastroenterology (The Inflammatory Bowel Disease Standards Group 2013). The most common food intolerances include dairy products, red meat, omega-6 fatty acids, wheat, yeast, alcohol and caffeine (Hou *et al.* 2011). Reduction of known irritants may help in maintaining remission and subsequently preventing decrease of energy.

3.5 Impact of IBD

The chronic and unpredictable nature of IBD has a negative impact on all aspects of individuals' lives and leads to significant impairment of QoL (Sainsbury & Heatley 2005, Lix *et al.* 2008, Magalhaes *et al.* 2014). The QoL of people with IBD is considerably

lower compared with the general population and is directly correlated with disease activity, being worse in active disease when compared with remission (Cohen 2002, Ghosh & Mitchell 2007, Burkhalter *et al.* 2015).

Disease-related concerns about the effects of medication, surgery, stoma formation, being a burden, intimacy and low energy levels are frequently reported (Levenstein *et al.* 2001, Carlsson *et al.* 2003, Farrell & Savage 2010). Often people have to plan their lives around toilet availability and at times they may not be able to leave the house (Dibley & Norton 2013, Norton *et al.* 2013, van der Have *et al.* 2014). The unpredictability of symptoms restricts individuals' freedom to be involved in everyday activities and fulfilling their roles in their private, social and professional sphere of life (Hall *et al.* 2005, Leso *et al.* 2015).

The embarrassing nature of the disease and socially unacceptable symptoms such as diarrhoea, urgency and risk of faecal incontinence in public may make people feel stigmatised (Dibley & Norton 2013) and prevent them from socialising and leading normal lives (Norton *et al.* 2013, van der Have *et al.* 2014). There seems to be a strong link between the severity of the condition and the ability to work. Patients who have regular flare ups are more likely to be unemployed due to IBD (European Federation of Crohn's and Colitis Association 2012). Greater level of IBD-related absenteeism from work contributes to reduced employment or promotion opportunities and creates additional financial strains (European Federation of Crohn's and Colitis Association 2012, Bajorek *et al.* 2015).

Co-existing depression, constant fear and anxiety about disease exacerbation, fear of hospital treatment, guilt because of the effects IBD have on family and an overwhelming sense of isolation are all key concerns and predict a more negative disease course and poorer response to treatment (Rubin *et al.* 2009, Kappelman *et al.* 2010, Mikocka-Walus *et al.* 2012). There is evidence that the course of the disease is worse in depressed patients (Graff *et al.* 2009b), therefore assessment of psychological co-morbidities such as anxiety, stress and depression is important to improve psychological well-being. These psychological symptoms combined with disease activity increase patients' risk of hospitalisation and surgery and further impair their QoL (Guthrie *et al.* 2002, Nordin *et al.* 2002, Lichtenstein *et al.* 2004).

Some patients may have difficulties understanding and accepting the IBD diagnosis and its long-term management. Concerns regarding pain, tiredness, fertility, fear of the hereditary aspects of the disease and risk to the family of developing IBD are frequently raised (Sewitch *et al.* 2001, Joyce *et al.* 2008, Burkhalter *et al.* 2015). Individuals with IBD are twice as likely to report unmet healthcare needs as the general population, at the same time barriers including long waits and availability of specialist care affect their perception of quality of care (Nurmi *et al.* 2012).

IBD is an ‘invisible’ condition, often a social taboo associated with stigma (Dibley & Norton 2013), and those with IBD use avoidance coping significantly more often than the general population, resulting in them leading more restricted lives (Graff *et al.* 2009a). Issues that are of concern for patients should be discussed with healthcare professionals through open and honest discussion, as IBD patients have often stated the need for professional support.

Preventative interventions should include treating co-morbidities, enhancing problem solving and personal control, facilitating mourning and grieving, reducing stress, enhancing positive appraisal of uncertainty, increasing social support and educating patients, family and others (Dudley-Brown 2002, Fuller-Thomson & Sulman 2006, Graff *et al.* 2009b). The contribution of fatigue to overall QoL and impact on the individual is not known. IBD patients with fatigue need to cope with fatigue within this complex and uncertain landscape of the whole IBD experience.

3.6 Summary

IBD is a lifelong disease with no current cure. Symptoms are unpleasant and anti-social, causing extensive embarrassment. Diagnosis is often delayed as symptoms may initially mimic other conditions. Diagnostic and surveillance tests such as colonoscopy are unpleasant and invasive. Flare-up of disease is unpredictable and can occur very rapidly. Drugs treatments can have side effects or cause new health issues. An increased risk of cancer and extraintestinal manifestations can be debilitating. There is a high lifetime risk of needing surgery, often repeatedly, and many live with a permanent or temporary stoma. There is also a risk of children inheriting a predisposition to IBD. IBD combined with fatigue limits peoples’ ability to live independent and fulfilling professional and personal

lives. Unsurprisingly IBD has a major impact on QoL for individuals and those close to them.

Chapter 4 Phenomenon of fatigue in chronic conditions and the methods to study it – A meta-study and synthesis of qualitative research

4.1 Introduction

The aim of this chapter is to review the qualitative literature from research in the field of fatigue, the fatigue experience of people with chronic conditions and the methodologies used to study it. This chapter sets out the body of knowledge and understanding of fatigue in chronic conditions, against which the findings from the present study are later compared and contextualised.

Although the literature review is presented here as Chapter 4, the information was gathered and analysed after all the empirical parts of the study had been conducted, including the drafts of all results chapters. This decision was based on the principles of descriptive phenomenology. In general the aim of qualitative research is to discover areas that are new to the world of science and research. It is generally advocated that the research process in descriptive phenomenology should not start from a review of the existing literature, as this may impact the researcher's ability to 'see' new things (Wolcott 2002, Holloway & Wheeler 2013).

To date, fatigue in IBD has received little attention in clinical practice, as evidenced by patients' complaints (Czuber-Dochan *et al.* 2013b), and the wider research literature as demonstrated in systematic reviews where only a limited number of studies have been identified (van Langenberg & Gibson 2010, Czuber-Dochan *et al.* 2013a). Additionally, the phenomenon of IBD-fatigue has neither been well described nor understood by patients or clinicians and is poorly managed (Czuber-Dochan *et al.* 2013a, Czuber-Dochan *et al.* 2014a). To gain an understanding of the concept of fatigue in IBD and how it impacts on people's lives, an exploration of fatigue in other chronic conditions (where fatigue has been extensively researched over the past few decades) was undertaken. For science to be cumulative, to build on knowledge and for a new study to be useful, a synthesis of the existing evidence is necessary (Light & Pillemer 1984).

Research papers are read not only to produce a literature review, or to add to the body of empirical knowledge, but also as an important part of developing methodological

knowledge (as is true for this PhD studentship) and ‘to see how others have addressed methodological challenges, or to spark off connections between our own areas of research and those of others’ (Green & Thorogood 2014, p.258). Many different definitions of experience exist. Experience could be used as a noun and/or a verb. The definition of ‘experience’ as a noun relates to a possession of a set of skills and knowledge, accumulated by participation in or observation of a particular phenomenon or event; on the other hand ‘experience’ as a verb, may mean partaking in a event (Stevenson 2010). The working definition of the word ‘experience’ is used here in its broadest sense that encapsulates its various forms and meanings.

The task of searching the literature on the studied phenomenon should be approached in a sufficiently broad manner to allow for differences within the phenomenon to be captured, but should also be sufficiently narrow to set boundaries and directions for literature retrieval (Paterson *et al.* 2001). To keep this review manageable, three chronic conditions were selected: cancer, multiple sclerosis (MS) and rheumatoid arthritis (RA). The rationale for this selection is based on the fact that these conditions are of autoimmune or inflammatory aetiology, as is IBD, and fatigue is frequently experienced and reported as one of the debilitating symptoms, either as a result of the disease process or a side effect of its treatment. Additionally, fatigue in these conditions has been a topic of research over the past two to three decades and there is already an existing body of knowledge on fatigue experience. Literature on myalgic encephalomyelitis, commonly known as chronic fatigue syndrome (ME/CFS), has not been included. In ME, fatigue is the primary condition, rather than a symptom of the condition. However, the literature on patients’ experience of living with CFS will be utilised in the discussion of the findings of the main study.

This chapter considers the following:

- A critique of the different literature review types and identification of the method for this review
- A description of the process of searching and selecting the literature
- A synthesis of the findings on fatigue in chronic conditions and methodologies used to study the concept
- A demonstration of the gaps in the evidence on fatigue in chronic conditions.

4.2 Type of literature review and a brief critique

With the growing amount of research literature, it is necessary to synthesise the body of knowledge, otherwise there is a risk of constantly ‘reinventing the wheel’. A successful and beneficial literature review is one that creates a firm foundation for advancing knowledge (Webster & Watson 2002); choosing the right approach is paramount for successful execution (Hannes & Lockwood 2012).

Reviewing and synthesising findings from qualitative research presents significant philosophical and practical challenges. Before the review could commence, it was necessary to decide on the exact type of review to be undertaken. The idea of research synthesis is not novel, and can be traced back many decades and even centuries (Booth *et al.* 2012). Antecedents to modern research synthesis have been traced back to the 17th century when astronomers found that combining data from related studies introduced greater precision to their individual observations (Petticrew 2001). Other early reviews related to inoculation against fever and typhoid fever in the early 20th century (Booth *et al.* 2012). All of those reviews, however, related to quantitative data, and had a formal procedure for synthesising quantitative studies. The label of meta-analysis was not introduced until the 1970’s (Cooper 2010), and was followed by the launch of the Cochrane Collaboration in 1993 (Booth *et al.* 2012).

The same extensive historical development cannot be presented for appraisal and synthesis of qualitative research. Nevertheless, the rising popularity of evidence-based practice and healthcare in the 1990s led to the recognition of the importance of research synthesis in other disciplines and research designs, including qualitative studies (Evans & Benefield 2001). The term ‘*qualitative meta-synthesis*’ was first introduced by Stern and Harris (1985), and the publication of the seminal work ‘*Meta-Ethnography: Synthesising Qualitative Studies*’ by Noblit and Hare (1988), presented an example of reviewing linked ethnographies, and provided researchers with a formal process of synthesising qualitative studies. Synthesis of qualitative research is therefore a relatively new technique (Jensen & Allan 1996), and its introduction has not been without its critics who see it as being less credible and less rigorous than meta-analysis of quantitative research (Paterson 2012). Knowledge generated through qualitative research can be somewhat tentative, and as such it has always attracted more criticism and a circumspect attitude than knowledge generated through positivist ‘*truth claim*’ approaches (Walsh & Downe 2005). Qualitative (interpretive) researchers are more interested in gaining insight and an understanding of the

phenomenon, and therefore, they endorse constructionist and post-constructionist approaches, rather than positivist approaches (Punch 2014). A singular explanation of the phenomenon with one coherent theory, as advocated by positivists, has also attracted criticism by postmodernists, as an over simplistic and reductionist way of presenting complex phenomena (Sandelowski *et al.* 1997, Campbell *et al.* 2003).

The current literature review is set against the backdrop of the critique and limitations on both sides of the paradigms presented above. A step towards the validation of qualitative literature synthesis methods was marked by its acceptance by the Cochrane Collaboration, following the publication of the Paterson *et al.*, (2001) text-book on meta-synthesis, providing step-by-step systematic and rigorous instructions on how to undertake a qualitative review. Meta-synthesis of qualitative research as a technique should therefore be viewed as parallel to meta-analysis used in quantitative research, with one important difference. The aim of meta-synthesis is to interpret, rather than aggregate the results, from different but inter-related qualitative studies (Walsh & Downe 2005). A review of qualitative research should be viewed as a search for a new insight and understanding of the essence of the phenomenon and an appreciation that the synthesis is ever-changing (Sherwood 1997).

Approaches to the synthesis of any body of literature take place on an aggregative / interpretive continuum (Weed 2005). The appeal and benefits of synthesising qualitative evidence lies in the possibility of strengthening the evidence, and providing more powerful explanations than that of a single study (Paterson 2012). The choice of synthesis method is generally driven by the aims of the review, however with a plethora of different review designs and little consensus on the optimal method to synthesise data, the type and process of the review can be difficult to decide on (Britten *et al.* 2002, Campbell *et al.* 2003, Gough *et al.* 2012). Fourteen different terms and approaches to qualitative literature reviews have been identified (Finfgeld 2003, Booth *et al.* 2012, Hannes & Lockwood 2012, Coughlan *et al.* 2013). Examples of common methodologies for the synthesis of qualitative reviews used in practice include: meta-ethnography (Noblit & Hare 1988, Britten *et al.* 2002), narrative summary (Evans & Kowanko 2000), meta-study (Paterson *et al.* 2001), grounded theory synthesis (Eaves 2001, Kearney 2001), critical interpretive synthesis (Dixon-Woods *et al.* 2006) and thematic synthesis (Thomas & Harden 2008). While this proliferation of different types of review may contribute to the development of more systematic and rigorous methods, the use of different terminology and a lack of consistent definitions of

the terms, add to the confusion in the meaning of different terms and of their scientific merits (Bondas & Hall 2007, Coughlan *et al.* 2013).

'Meta-synthesis' is a generic term describing a family of methodologies which synthesises the findings of qualitative research (Thorne *et al.* 2004, Dixon-Woods *et al.* 2005). The prefix *'meta'* means 'higher, more developed or changed and transformed' (Stevenson 2010); therefore, meta-synthesis of qualitative research attempts an advanced interrogation and analysis of the results, with the aim of providing greater understanding of the contextual dimension of the studied phenomenon to inform healthcare policy-making and to influence knowledge development. Meta-synthesis has been defined as a process of *'bringing together and breaking down of findings, examining them, discovering the essential features, and in some way, combining phenomena into a transformed whole'* (Schreiber *et al.* 1997, p.314). The goal of meta-synthesis is to produce a new and integrative interpretation of the findings of primary qualitative studies and to create a comprehensive understanding of the studied phenomenon (Finfgeld 2003, Hoon 2013).

Following the consideration and analysis of the different types of literature review, and reading examples of literature review papers, a meta-study as a form of meta-synthesis of qualitative research was considered most suited to conducting this systematic review. Meta-study is rooted in a constructivist orientation to epistemology and it aims to understand how individuals' knowledge about a phenomenon is constructed and reconstructed. It also emphasises the link between methods, theory and the findings and conclusions, and considers how the theoretical and methodological contexts have shaped the research findings (Paterson *et al.* 2001). The idea of a constructivist perspective was particularly relevant to the aim of this review, as it sought to critically examine and reshape knowledge about fatigue in chronic conditions. The meta-study framework (see Table 4-1) provided explicit guidelines on study selection, appraisal, data extraction and synthesis of findings (Paterson *et al.* 2001), and fitted well with the aims of this literature synthesis. The use of the framework also helped to achieve a systematic, rigorous and transparent review protocol.

Qualitative research is the focus of this meta-synthesis. The value of bringing together studies on a similar topic is that each additional study adds 'weight' to the findings that enlarges the interpretive possibilities of the results (Noblit & Hare 1988, Paterson *et al.* 2001, Pope *et al.* 2007). Each study holds the potential to add new or additional insights and to contribute to the overall picture of the studied phenomenon, in this case fatigue in

the selected chronic conditions and IBD. Use of different studies from varied backgrounds (e.g. different conditions as is a case in this review) in the interpretive process can be seen as multi-vocal interpretation of a phenomenon, similar to individual participant's voices in a single study (Zimmer 2006).

Meta-synthesis also adds to the understanding of the methodologies used to study the topic of fatigue and how different methodologies have contributed to the development of knowledge in this area. The results of the review are expressed in narrative form, for both empirical data and chosen methodologies.

Table 4-1 Process of meta-study (Paterson et al 2001)

Components	Tasks
Formulation of a research question	Formulation of research question Choosing a theoretical framework Generating workable definitions of key concepts Anticipating outcomes of the project Developing evaluation criteria for included studies
Study selection and appraisal	Identifying inclusion/exclusion criteria Specifying appropriate data sources Screening and appraisal procedure Retrieving studies
Meta-data analysis	Developing coding system Identifying analytic strategy Categorising the data Discussion and interpretation of findings
Meta-method	Specifying methodological characteristics Elaborating on how methodological characteristics influence research findings
Meta-theory	Identifying major schools of thought that are represented in the theoretical framework and emerging theory of reports Relating theory to the larger social, historical, cultural and political context Uncovering significant assumptions underlying specific theories
Meta-synthesis	Critically interpreting the strengths and limitations of the various discrete contributions to the field Uncovering significant assumptions underlying specific theories Searching for alternative explanations for paradoxes and contradictions within the field Determining which existing theoretical stances are and are not comparable and why? Proposing alternative theoretical structures within which existing knowledge can be interpreted
New theoretical interpretation and dissemination of findings	Determining appropriate audiences Determining appropriate vehicles for dissemination of the findings Writing and presenting the findings

4.3 Review aims and objectives

The aim of this review is to synthesise the experience of fatigue as reported by adults diagnosed with the selected chronic conditions and to explore the impact that fatigue has on individuals' daily life. Additionally, the review aimed to identify and analyse the qualitative methodologies used to study the experience of fatigue.

The specific objectives of the meta-synthesis were to:

- Explore and synthesise the experience of fatigue as reported by individuals diagnosed with a chronic condition (cancer, multiple sclerosis and rheumatoid arthritis)
- Analyse the language used to describe symptom of fatigue, and the similarities and differences that exist within and between conditions
- Analyse areas of commonalities and differences in the impact of fatigue on individuals' with different conditions and the extent of that impact
- Identify and appraise methods used to study the phenomenon of fatigue in chronic conditions and determine if and how the use of different methods appeared to impact on the study results.

4.4 Literature search and selection process

Despite best efforts to identify primary research relevant to the research aims, it is extremely difficult to identify all the available qualitative research (Cooper & Lindsay 1998, Paterson *et al.* 2001, Barroso *et al.* 2003). Every effort was made to identify as wide a range of literature on fatigue as possible, through developing a comprehensive search strategy. A systematic search was conducted using several electronic databases to identify relevant qualitative research on fatigue in the selected chronic conditions. The following electronic databases were individually and systematically searched: Medline, CINAHL, EMBASE, PsycInfo, British Nursing Index (BNI), the Web of Science including Science Citation Index (SCI) and Social Science Citation Index (SSCI). These bibliographic databases enable researchers to gain access to a large number of original studies in healthcare literature and to the most recent worldwide research publications (Craig & Smith 2007, Burns & Grove 2009). When developing the search strategy, both subject heading searching (MeSH) and free text searching were used to maximise citation retrieval (Hart

1998, Barker 2010). The Boolean operator ‘OR’ was used within each facet to maximise the searches and operator ‘AND’ was utilised between the facets to combine and to identify the searches specific to the topic of interest. The search strategy was developed using search terms related to fatigue, specific chronic conditions and study design (Table 4-2). Fatigue occurs in many conditions, including Parkinson’s disease, fibromyalgia, stroke, Human Immunodeficiency Virus (HIV), diabetes, chronic obstructive pulmonary disease and others, and to include all of them in the review would have been unmanageable. The risk of over-limiting the search results by excluding these conditions was off-set by not limiting the publication year on searches for cancer, multiple sclerosis and rheumatoid arthritis literature. The searches were performed between June and July 2014, and updated on 15th October 2014.

Table 4-2 Facet search terms used for literature searching

Fatigue	Chronic conditions	Study design
fatigue (MeSH) fatigue*	chronic disease (MeSH)	qualitative research
tired*	chronic disease*	(MeSH)
low energy*	chronic condition*	qualitative research*
vigour*	cancer/tumour/neoplasm	qualitative stud*
vitality*	(MeSH)	phenomenology*
exhaustion*	cancer*	ethnography*
weakness*	malignan*	grounded theory*
lethargy (MeSH)	multiple sclerosis (MeSH)	interpretive research*
lethargy*	multiple sclerosis*	interpretive stud*
	rheumatoid arthritis	
	(MeSH)	
	rheumatoid arthritis*	

Key: * free term search or truncation

Searching with the ‘Suggest Subject Term’ box ticked allows the database to use a thesaurus and suggest the closest corresponding subjects to the original term. This method expands the number of retrieved references. When given the option, the ‘Explode’ box was ticked and ‘All subheadings’ were selected to increase the number of hits. Using the free-text search on the other hand, allows searching for the phrase in different fields including abstracts and titles. When searching for literature in relation to a specific question, it is important to be as broad as possible, but at the same time to identify citations relevant to the topic (Craig & Smith 2007). Therefore, limits in terms of ‘English language’, ‘original article’, ‘humans’, ‘full paper’ and ‘all adult’ were applied in order to identify papers most relevant to the study topic. Due to time restrictions and no funds for translation, only papers

published in English were selected. Although the search strategy was systematic and specific to the study aims, it nonetheless generated a large number of irrelevant and non-research based publications. Following the removal of duplicates, a total of 689 references were identified and imported to EndNote. The details of the search handling process and number of selected references at each stage are presented in Figure 4-1.

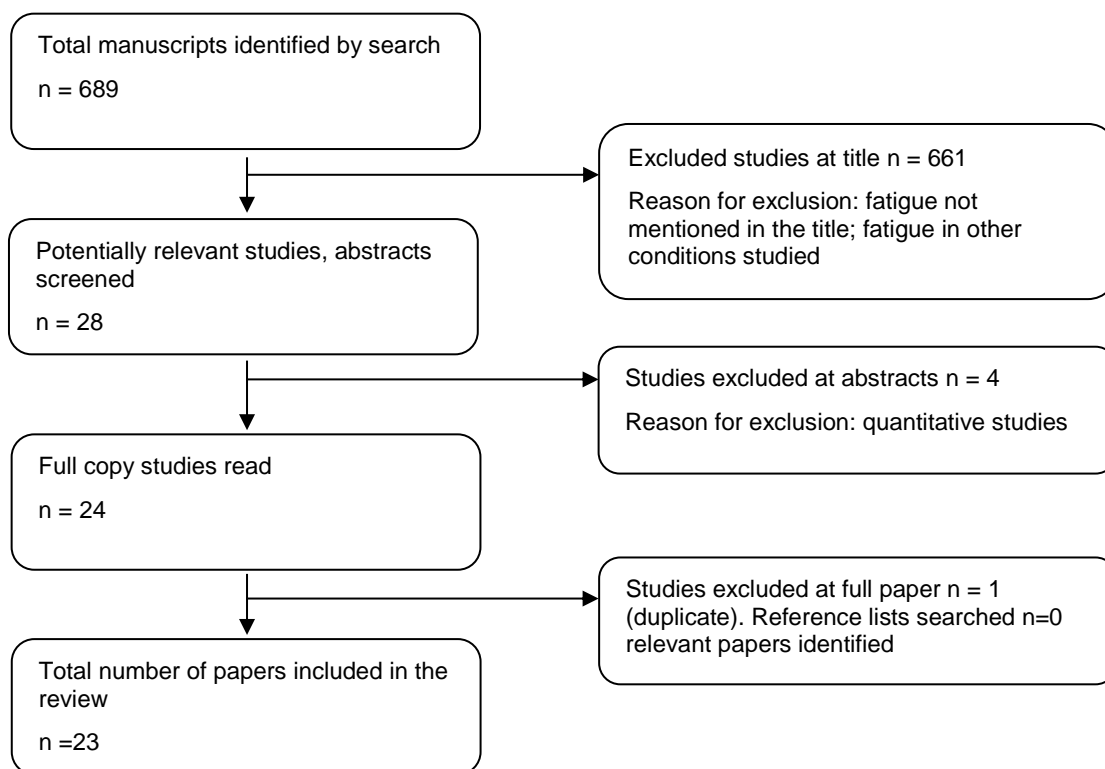


Figure 4-1 Flowchart of citation retrieval and papers selection process

The main inclusion criterion was the relevance of the study to the research topic. Papers were included if they met the following eligibility criteria:

- Presented primary qualitative studies on fatigue and fatigue experience reported by patients in cancer, multiple sclerosis and rheumatoid arthritis
- Reported findings where data were collected in direct communication (face to face or over the phone)
- Adult patients over 18 years of age
- Published in English
- All types of qualitative methodologies

- Qualitative results in mixed-methods studies were included. If a study reported on multiple conditions, or comparison with healthy population, only data relevant to one of the selected conditions were extracted if reported separately within the paper
- Reported findings in themes supported by patients' quotes
- Full copy paper available.

Papers were excluded if they:

- Focussed on children
- Reported experience of fatigue as perceived by healthcare professionals and/or next of kin
- Collected data via the internet, patient diaries or free text questionnaires as some accounts may be short and lack the necessary in-depth detail, compared to oral accounts
- Explored multiple concurrent symptoms but did not report on experience of fatigue separately
- Were quantitative in design
- Studied fatigue in chronic conditions other than those selected for this review
- Studied fatigue in end of life care
- Were published in languages other than English.

Studies that did not meet the inclusion criteria were retained, if relevant, for background information or literature supporting the discussion of the findings of this thesis. To maximise the number of papers, the reference lists of all included papers were hand searched to identify further relevant literature, however no new papers meeting the inclusion criteria were found.

4.4.1 Quality appraisal

Prior to conducting the meta-synthesis, each paper was critically appraised for its methodological consistency and the quality of the content presented. Critical appraisal is a process of systematically examining research evidence to assess its validity, rigour (trustworthiness) and its relevance to the review question (Hill & Spittlehouse 2003, Cohen & Crabtree 2008). Assessing study quality is an essential step, and the quality of any systematic review depends on the quality of the studies included in it (Lloyd Jones 2004, Hannes 2011). The process of assessing the papers' quality was challenging, because

despite there being many different ways of assessing qualitative papers, there is no consensus on the most appropriate assessment tool (Popay *et al.* 1998, Mays *et al.* 2005, Hannes 2011). There is also a lack of agreement on the best assessment approach; should this be specific to the study methodological design, or would more generic criteria for evaluating studies of any qualitative design be sufficient? (Sandelowski & Barroso 2003). Additionally, the issue of studies' quality remains controversial; with some researchers advocating that only the best studies (best evidence) should be included in a review, and others arguing that no study should be excluded based on its quality, as even a less comprehensive, and less rigorous study has the potential to add to the body of evidence (Slavin 1995, Dixon-Woods *et al.* 2007). For this review, the latter position was taken.

Many of the criteria used to assess the quality of qualitative research are similar irrespective which method is adopted. In this meta-synthesis, the studies appraisal was undertaken by adapting Paterson *et al.* (2001) categories and Critical Appraisal Skills Programme (CASP) guidelines (Public Health Research Unit 2006) (Appendix IV). These tools were selected because they complement each other, make the fewest epistemological and methodological assumptions, and appeared most applicable across the spectrum of different qualitative methods. The results of quality assessment of the included studies are critiqued in the results section of this chapter.

4.4.2 Data extraction

The method of data extraction should be led by the purpose of the literature review. This is typically an iterative process of reading, extracting, and data analysing in several cycles as immersion in the data takes place and key themes emerge (Noyes & Lewin 2011). Different reviews may require a different data extraction template and examples of several approaches to extraction of qualitative data are available (Paterson *et al.* 2001, Petticrew & Roberts 2006, Briggs & Flemming 2007, Noyes & Popay 2007, Pope *et al.* 2007, Munro *et al.* 2008).

For this review the data extraction form as developed by Paterson *et al.*, (2001) (Appendix IV) was used as it covers all main features of the primary research and provides the basis for the three components of the meta-study, that is meta-data, meta-methods and meta-theory. Due to time limits and feasibility of the task all papers were read in full, but only data reflecting the aims of the review were extracted as specified in the extraction template.

This selective approach to data extraction is useful where a large volume of data or studies have been included in a review (Pearson 2004).

4.4.3 Data analysis

Meta-data analysis is the process aiming to analyse the data from the selected studies and to create an integrated body of knowledge on the studied phenomenon, in this case fatigue in the selected chronic conditions of cancer, multiple sclerosis (MS) and rheumatoid arthritis (RA). All the papers were read in full and re-read in parts to gain a comprehensive understanding of their content. The process of meta-data analysis is not a static one and it can be adapted to the research question (Paterson *et al.* 2001).

To analyse the reviewed data and to create a comprehensive understanding of the phenomenon of fatigue, the steps of continuous comparative analysis method as proposed by Paterson *et al.*, (2001) were used (Table 4-3).

Table 4-3 Steps of continuous comparative analysis method
(Paterson et al 2001, p.64-65)

Steps	Description of the process
Step 1	Read primary research report in detail. Make notes about the concepts, key metaphors, and phrases that best describe the phenomenon
Step 2	Compare and contrast the data in this primary research report with the data in other studies, as a whole or in subgroups, noting similarities and differences between the key metaphors for each study
Step 3	Hypothesise about the nature of the relationships between studies and depict these relationships in a schematic representation
Step 4	Translate the primary research studies into one another by determining how the key metaphors of each study relate to those of other accounts, refining these translations until the interpretations of the phenomenon is described in a way that is faithful to the interpretations of the original data; that is, it accurately portrays the shared and unique findings of the included research studies

Following this process allowed for direct comparison of the results between studies. The primary study results on fatigue in IBD were then compared against the results of the literature review to validate the new findings and to identify similarities and differences between the descriptions of the phenomena (Chapter 10).

4.5 Results

Twenty three papers met the inclusion criteria and formed the basis of the meta-synthesis.

4.5.1 Summary of reviewed papers

Tabulation of the results makes it easier to locate the main characteristics and variables of the studies. The key features of the included studies are summarised in Table 4-4 and the full extracted data are presented in Appendix V. Five studies reported fatigue in MS (Stuifbergen & Rogers 1997, Flensner et al. 2003, Olsson *et al.* 2005, Mills & Young 2008, Blaney & Lowe-Strong 2009), three in RA (Hewlett *et al.* 2005, Repping-Wuts *et al.* 2008, Nikolaus *et al.* 2010a) and fifteen in cancer, of which eleven studies were conducted with a cancer population only (Pearce & Richardson 1996, Magnusson *et al.* 1999, Lindqvist *et al.* 2004, Porock & Juenger 2004, Potter 2004, Olson *et al.* 2007, Wu & McSweeney 2007, Tsai *et al.* 2010, Pongthavornkamol *et al.* 2012, Siegel *et al.* 2012, Spichiger *et al.* 2012), two with cancer and healthy individuals (Glaus *et al.* 1996, Gledhill 2005), one with cancer and chronic obstructive airways disease (COAD) (Ream & Richardson 1997) and one in cancer and chronic fatigue syndrome (CFS) (Bennett *et al.* 2007). Most studies had no stated theoretical orientation (Table 4-4).

Table 4-4 Summary of research primary features of studies included in meta-synthesis in chronological order

Code	Authors/Year/ Country	Condition/ Sample	Methodological design	Data analysis	Theoretical orientation	Main findings
001	Glaus et al. (1996) Switzerland and UK	Cancer all except brain tumour (n 20) 9F, Healthy individuals* (n 20)	Grounded theory	Content analysis and constant comparison	Theory generation	Fatigue categorised into physical, affective and cognitive expressions; Fatigue involved decreased physical performance, extreme, unusual tiredness, weakness and unusual need for rest.
002	Pearce & Richardson (1996) UK	Cancer (n 4) type of cancer or gender not stated	Phenomenology (not stated which, but interpretive)	Thematic analysis (Giorgi 1975)	None stated (Human experience as it's lived)	There is a shared and individual experience of fatigue incorporating the nature of fatigue, causes, consequences, strategies for coping, and the trajectory of the fatigue experience.
003	Ream & Richardson (1997) UK	Cancer all types (n 9) 8F COAD* (n 6)	Phenomenological approach (not stated which, but descriptive)	Moustakas method (1994)	None stated (Subjective everyday experience)	Fatigue depicted as a complex phenomenon; Physical and mental sensations are embodied in fatigue; Fatigue impacts on everyday functioning; Fatigue impact and the emotional feelings evoked by fatigue impacts on perceived control.
004	Stuifbergen & Rogers (1997) USA	Multiple sclerosis (n 13) 10F	Qualitative descriptive design (specific design not stated)	Content analysis and constant comparison	None stated	Fatigue was ever-present, had pervasive impact on life; The exacerbation of MS symptoms increased fatigue; Self-care strategies included energy conservation, recharge efforts, enhancing resistance to fatigue, and temperature control.
005	Magnusson et al. (1999) Sweden	Cancer all types (n 15) 8F	Grounded theory	Grounded theory, constant comparison method	None stated (Understanding of the concept of fatigue)	Fatigue illustrated as a process, described by metaphors; Fatigue described as multidimensional symptom; Instead of expressing the experience of fatigue, the consequences of fatigue or actions due to consequences were presented.
006	Flensner et al. (2003) Sweden	Multiple sclerosis (n 9) 5F	Phenomenological approach (Husserl's philosophy)	Karlsson (1995) five step analysis	The empirical phenomenological psychological method (Karlsson 1995)	Fatigue is time-consuming and all absorbing, involving the body and the whole human being; Non-constructive perceptions in terms of energy loss, emotional afflictions, dependency and restrictions of life; Constructive perceptions involves a desire to accept life and strive for a better situation.

Code	Authors/Year/ Country	Condition/ Sample	Methodological design	Data analysis	Theoretical orientation	Main findings
007	Lindqvist et al. (2004) Sweden	Cancer (n 4) 3F Palliative care	Phenomenological- hermeneutic approach	Structural analysis in step one, thematic analysis in step two (Ricoeur 1976)	Ricoeur philosophy to understand the ways of being in the world	Meaning of fatigue connected with incurable cancer is a lived bodily experience of approaching death; This explains paradoxes such as struggling in vain against fatigue and hoping to overcome fatigue but expecting failure; A struggle between body and mind, between bodily experience and intellectual understanding.
008	Porock & Juenger (2004) USA	Cancer (melanoma or renal cell carcinoma) (n 10) 3F	Qualitative (specific design not stated)	Content analysis	None stated	The strongest meaningful advice from the participants was to 'be strong and go with the flow'; Boredom associated with cognitive fatigue and inability to accomplish work and other tasks.
009	Potter (2004) UK	Cancer all types (n 6) 5F	Phenomenology, Heidegger's hermeneutic circle	Thematic content analysis (Colazzi 1978, Burnard 1991)	None stated	Meaning of fatigue was intertwined with the process of adjusting to living with a terminal illness, impossible to separate the two; Coping strategies that would normally be of use to fatigued individuals were shown to have little /no benefit; Sensitive communication about fatigue and its meaning to the patient may assist adjustment and generate hope;
010	Gledhill (2005) France	Cancer all types (n 24) 14F Healthy subjects* (n 24)	Grounded theory	Thematic analysis and constant comparative analysis	Theory generation	Fatigue more severe in patient group than in healthy subjects; Fatigue has three dimensions, physical, affective & cognitive; The linguistic descriptions of fatigue confirmed differing perceptions of fatigue and a the negative aspects of fatigue and suffering; Individuals respond differently to fatigue.
011	Hewlett et al. (2005) UK	Rheumatoid arthritis (n 15)12F	Qualitative (specific design not stated)	Thematic analysis and constant comparison	None stated	Severe, extreme and overwhelming fatigue, not related to activities and unresolving, different from normal tiredness; There are physical, cognitive and emotional components of fatigue with far-reaching effects on physical activities, emotions, relationships, social and family roles; Self-management strategies but with limited success; Most did not discuss fatigue with clinicians but when they did, they felt it was ignored.

Code	Authors/Year/ Country	Condition/ Sample	Methodological design	Data analysis	Theoretical orientation	Main findings
012	Olsson et al. (2005) Sweden	Multiple sclerosis (n 10) 10F	Phenomenological hermeneutic (Ricoeur 1976)	Structural analysis	None stated	The body was experienced as a barrier and an enemy of survival, fatigue gave rise to an experience of being absent; Fatigue led to a feeling of not being able to participate in the surrounding world; The feeling of being an outsider and lacking the ability as a healthy person interpreted as a form of suffering.
013	Bennett et al. (2007) Australia	Cancer (breast) (n 16F) Chronic fatigue syndrome* (n 12)	Qualitative (specific design not stated)	Grounded theory tradition	None stated	Patients suffered disabling behavioural consequences of the symptom complex.
014	Olson et al. (2007) Canada	Cancer all types (n 27) 12F	Ethoscience method	Componential analysis (dyadic, triadic, Q-sort by Spradley 1979)	Adaptation model, Stress theory	Although tiredness, fatigue and exhaustion are all manifested by the same 5 attributes (changes in emotional, cognitive, muscular function, decreasing control over body processes and decreased social interaction) the qualitative differences in the manifestations support the assertion that they are distinct states.
015	Wu & McSweeney (2007) USA	Cancer (breast, non-Hodgkin's lymphoma) (n 10F)	Phenomenological approach as developed by Husserl and Heidegger	Content analysis	Embodiment and self-body relation	Fatigue described as much more than just being tired; Inability to anticipate the scope of fatigue and lack of awareness of strategies to combat fatigue was distressing; Various individual strategies, based on personal experience, were developed to regain a sense of control.
016	Mills & Young (2008) UK	Multiple sclerosis (n 40) 32F	Mixed-methods study with qualitative phase	Framework approach of theory grounded in the data (Pope et al 2000)	None stated	Despite variance across patients, fatigue could be described within the derived themes and framework; Fatigue defined as reversible motor and cognitive impairment, with reduced motivation and desire to rest; It could appear spontaneously or may be brought on by mental, physical or environmental factors; It can be relieved by daytime sleep or rest and could occur at any time but was usually worse in the afternoon.

Code	Authors/Year/ Country	Condition/ Sample	Methodological design	Data analysis	Theoretical orientation	Main findings
017	Repping-Wuts et al. (2008) The Netherlands	Rheumatoid arthritis (n 29) 17F	Qualitative (specific design not stated)	Framework analysis	None stated	Fatigue verbalised as everyday experience with a variety in duration and intensity, sudden and exhausting; The consequences are overwhelming and influence patients' everyday tasks, attitudes and leisure time; Patients are left to find their own management strategies; Most patients did not discuss fatigue with clinicians explicitly, accepting fatigue as part of the disease.
018	Blaney & Lowe-Strong (2009) Northern Ireland	Multiple sclerosis (n 10) 7F	Phenomenological approach (specific design not stated, but interpretive, no references)	Inductive analysis	None stated	Increase in the severity in communication symptoms and the onset of new communication symptoms when experiencing fatigue; The complex interplay between symptoms of fatigue and communication, strategies employed to manage these symptoms and societal attitudes was reported in 'barriers to participation'.
019	Nikolaus et al. (2010) The Netherlands	Rheumatoid arthritis (n 31) 23F	Qualitative (specific design not stated)	Framework approach, combined deductive and inductive elements of analysis	None stated	Inter-individual differences in the experience and impact of fatigue; Varying forms of fatigue were described; Different patterns in emotions, consequences and management; Younger women with multiple roles were more vulnerable to the negative impact of fatigue; Patients also reported positive aspects of fatigue.
020	Tsai et al. (2010) Taiwan	Cancer (breast) (n 15F)	Qualitative (specific design not stated)	Content analysis	None stated	Factors related to fatigue arose from treatment, symptom distress and the impact of their emotions; Fatigue was interpreted as an inevitable normal reaction, and participants were embarrassed to share its occurrence with others; Although fatigue made participants suffer, they used psychological adjustments, practical changes and support systems to decrease fatigue.

Code	Authors/Year/ Country	Condition/ Sample	Methodological design	Data analysis	Theoretical orientation	Main findings
021	Pongthavornkamol et al. (2012) Thailand	Cancer (lung or colorectal) (n 10) 5F	Ethnoscience	Componential analysis	None stated	The primary meanings of fatigue in the Thai data were related to temporality, whereas the primary meanings of fatigue in the Canadian data were related to the location of the fatigue (mind/body); The findings help to understand the social construction of fatigue.
022	Siegel et al. (2012) USA	Cancer all types (n 35) 18F	Qualitative (specific design not stated)	Content analysis	None stated	Patients who identified cancer-related treatment as the master attribution for fatigue seemed less distressed about the symptom; Multiple causes of fatigue e.g. combination of cancer, treatment and nonthreatening causes were also offered; Patients seemed to resist identifying disease severity as a cause and appeared motivated to normalise the symptom, decreasing its threatening impact.
023	Spichiger et al. (2012) Switzerland	Cancer (breast, lung, colorectal, lymphoma) (n 19) 11F	Grounded theory	Grounded theory	None stated	At the start of chemotherapy, health professionals informed patients that common side effects include fatigue; While all participants experienced different dimensions of fatigue, all were willing to endure it for the sake of an expected improvement; Individuals' fatigue experiences depended largely on their particular life and illness circumstances; Most engaged in fatigue-related self-care activities and managed the symptom on their own; Communication with or input from health professionals was virtually absent during chemotherapy.

Key: F – female, * - only data related to the selected conditions (cancer, MS and RA) were included in the review

4.5.2 Fatigue and its impact on patients' lives

The extracted findings for meta-data (Appendix VI) were compared and contrasted for similarities and differences between the selected conditions, from which five themes were identified: (1) description and nature of fatigue; (2) components and trajectory of fatigue; (3) antecedents and aggravating factors of fatigue; (4) pervasive impact and consequences of fatigue on life; (5) helpful and unhelpful strategies for managing fatigue. The themes represented across the reviewed papers are presented in Appendix VII and are discussed below.

4.5.2.1 Theme 1 Description and nature of fatigue

Fatigue has been described as overwhelming and unpredictable across all three conditions. It can have rapid onset, from one minute to another, with no or little warning. The sudden onset of fatigue was compared to being '*hit by a tidal wave*' (MS) (Stuifbergen & Rogers 1997), '*your battery just run dry*' (cancer) (Porock & Juenger 2004) or '*like energy drained from me*' (RA) (Hewlett *et al.* 2005). Being fatigued was to be '*worn out*' (Repping-Wuts *et al.* 2008), to have little or no energy to do physical activities, having problems concentrating and having no motivation '*can't be bothered*' (Mills & Young 2008), a '*total wipe out*' (Hewlett *et al.* 2005).

Fatigue was reported as difficult to describe due to its subjective, invisible but multidimensional nature, '*now I'm lost for a word*' (Bennett *et al.* 2007). Various terms were used to try and describe fatigue such as: '*lethargy*', '*tired*', '*exhausted*', '*shattered*', '*weak*', '*listless*', '*no energy*', '*heavy body*'. All these terms relate to physical aspects of fatigue. Some other terms like '*unable to concentrate*', '*the blues*', '*memory problems*', related to aspects of cognitive fatigue. Most terms describing fatigue were used interchangeably, or participants used more than one term at the same time to try and describe their experience. Olson *et al.*, (2007) in their study of cancer fatigue in Canada presented tiredness, fatigue and exhaustion as significantly different, but linked concepts. Pongthavornkamol *et al.*, (2012) conducted a similar study with cancer patients in Thailand to compare the words, phrases and meaning of fatigue in Canadian and Thai populations. They concluded that there were some similarities between the descriptions of fatigue in both groups, however there were also many differences that could be attributed to social and cultural constructions of illness and its meaning.

Metaphors were frequently used. Fatigue was compared to '*being heavy as lead*', '*several tons of sandbags*' (Olsson *et al.* 2005), '*like having a flu*' (Ream & Richardson 1997), '*being like a zombie ... like a vegetable*' (Porock & Juenger 2004), '*like a rag doll*' (Wu & McSweeney 2007) or '*like the stuffing had been taken out of them*' (Ream & Richardson 1997). Participants were also keen to differentiate between fatigue and 'normal' tiredness (Wu & McSweeney 2007, Spichiger *et al.* 2012). Tiredness was related to and could be explained by physical and mental activities, and was expected and deserved (Hewlett *et al.* 2005). Fatigue on the other hand was perceived as 'abnormal tiredness' not related to or not fully explained by activities or poor sleep (Bennett *et al.* 2007, Nikolaus *et al.* 2010b).

Fatigue as a '*paralysing power*' could '*invade*' the whole body or just certain, mainly peripheral, parts of the body (Stuifbergen & Rogers 1997). Localised fatigue would present as sensations of heavy limbs, stiff shoulders, pain, heat and stinging (e.g. eyes stinging), while general fatigue would involve both physical and mental sensations such as feelings of heaviness and pain of the whole body, yawning and sleepiness, breathlessness, poor concentration and memory problems.

Fatigue was presented as either a constant or intermittent process with fluctuating severity and duration; however there was no single pattern of daily or weekly fatigue (Pongthavornkamol *et al.* 2012). It was described as being on '*the millennium wheel ... one moment you are on a high, the next on a low*' (Gledhill 2005). Generally, less severe fatigue was reported in the morning and worsened as the day progressed. Many participants did not experience refreshing or fully refreshing effects of sleep and rest. Severe fatigue was portrayed as all-consuming and debilitating. Severity of fatigue was reflected in some studies by the terminology used e.g. '*exhausted*', '*completely wiped out*', or '*inability to do things*'.

4.5.2.2 Theme 2 Components and trajectory of fatigue

Physical, cognitive and emotional (or affective) components of fatigue were presented across nine studies covering cancer and RA, but not MS. In MS studies, greater emphasis was put on the impact of fatigue on people's lives, rather than on the description of the different domains of fatigue. In cancer and RA, physical fatigue was presented as feeling unusually tired, slowing down, lacking strength to carry on or to undertake activity, reduced stamina, heaviness, difficulty or inability to walk and excessive desire to rest (Glaus *et al.* 1996, Gledhill 2005, Hewlett *et al.* 2005, Olsson *et al.* 2005, Olson *et al.* 2007).

Manifestations of cognitive fatigue were demonstrated by difficulty in concentrating, reasoning and problem solving (Glaus *et al.* 1996, Ream & Richardson 1997, Gledhill 2005, Hewlett *et al.* 2005, Olsson *et al.* 2005, Olson *et al.* 2007). Participants had problems with memory and recall, reduced creativity and lucidity (Ream & Richardson 1997, Gledhill 2005, Hewlett *et al.* 2005). Emotional or affective fatigue involved mood swings, frustration, irritability, aggressiveness, lack of motivation, malaise, anxiety, depression, and intrusive thoughts (Gledhill 2005, Repping-Wuts *et al.* 2008).

The trajectory of fatigue was often placed in relation to the primary illness and its onset. Although, the manifestation of fatigue was different for different participants (irrespective of the condition), for some it started in the pre-diagnosis stage (and triggered the individual's contact with healthcare professionals), whilst for others fatigue was first experienced during or after medical or surgical treatment. In RA and MS populations fatigue was closely related to relapse, more severe illness and presence of other unpleasant symptoms e.g. pain.

4.5.2.3 Theme 3 Antecedents of fatigue and aggravating factors

Multiple factors were reported as affecting fatigue across all three conditions (Table 4-5). The primary illness (cancer, MS and RA), the illness process (deterioration or relapse of the condition) and treatment were reported to be the main antecedents to fatigue. In cancer patients chemotherapy was almost always a trigger for fatigue (Pearce & Richardson 1996, Potter 2004, Tsai *et al.* 2010, Siegel *et al.* 2012, Spichiger *et al.* 2012). Chemotherapy also brought on other symptoms such as nausea, vomiting and loss of appetite, which in turn aggravated fatigue.

There were many similar factors causing or aggravating fatigue in all three conditions such as pain, poor sleep quality and sleep disturbance. Physical everyday activities and trying to do too much were seen as contributing to fatigue, but equally decreased physical activity was perceived as contributing to greater levels of fatigue (Glaus *et al.* 1996, Stuifbergen & Rogers 1997, Hewlett *et al.* 2005, Mills & Young 2008, Repping-Wuts *et al.* 2008). Other co-morbidities were also perceived as aggravating fatigue (Pearce & Richardson 1996, Mills & Young 2008, Siegel *et al.* 2012). Nutritional factors (poor nutrition and loss of appetite) were reported in cancer and MS studies (Pearce & Richardson 1996, Stuifbergen & Rogers 1997, Gledhill 2005), but not in RA. MS patients also reported fatigue to be linked with '*food ingestion*' and alcohol intake (Mills & Young 2008). It is however, not

clear which aspects (the act of eating, poor nutritional value of food, amount of food or alcohol, or the process of digestion) contribute to higher fatigue levels.

Table 4-5 Antecedents and factors aggravating fatigue

Cancer*	MS**	RA***
cancer, illness process, treatment (chemotherapy, radiotherapy), medication, treatment after-effects	MS and MS relapse	RA, use of medication
pain, discomfort, headaches	pain	RA/pain, stiffness in the joints
poor or loss of appetite, nausea, vomiting, malnutrition, weight loss	poor nutrition, alcohol intake, food ingestion	
sleep disturbance, poor sleep	lack of rest and sleep, poor quality disturbed sleep, nocturnal sleep often un-refreshing	poor sleep, unrest, wakening
stress	perceived psychological stress related to family, work, socioeconomic	stress
emotions caused by becoming ill, unhappiness, uneasiness, negative emotions, loneliness, symptom distress, symptom burden	emotionally laden problems, psychological distress, mental activity	
depression, antidepressant	depression, anxiety	
older age		older age
co-morbidities, anaemia symptoms associated with other conditions such as menopause, migraine, dyspnoea, and breathlessness	infections	co-morbidity, disability
tiredness and low energy levels, living and working situations	lifestyle patterns, physical activity, physical exertion, trying to accomplish too many tasks in one day, long periods of inactivity or immobility	everyday tasks, doing too much; having to work harder, tasks take longer, doing too much, decreased physical activity, disability
multiple attributions and explanatory ambiguity	environmental factors : heat, direct intense sunlight, humidity, cold, warm room, hot shower	no reason, fatigue often not earned and unresolving

Key: Studies reporting factors aggravating fatigue: Cancer*- Pears & Richardson (1996), Potter (2004), Gledhill (2005), Bennett *et al* (2007), Tsai *et al* (2010), Siegel *et al* (2012), Spichiger *et al* (2012); MS** - Stuifbergen & Rogers (1997), Mills & Young (2008); RA*** - Hewlett *et al* (2005), Repping-Wuts *et al* (2008)

Psychological factors such as stress, anxiety, depression, negative feelings and symptom-related distress were identified in cancer and MS to increase fatigue, but these factors (except stress) were not reported, and possibly were not studied, in RA studies. This may be explained by a greater uncertainty and unpredictability of the disease progression in cancer and MS. Also cancer patients linked greater levels of fatigue to negative emotions related to death and dying. In MS patients, environmental factors such as extremes of temperatures and humidity, were reported to increase fatigue. Despite many factors being identified as aggravating fatigue, there were also ambiguities in terms of trying to explain the reasons for fatigue, and some factors (e.g. sleep, physical activity) were presented as both cause of, and solution to, fatigue. There was an overwhelming evidence that fatigue is attributed to multiple factors, and in many cases fatigue could not be easily explained.

4.5.2.4 Theme 4 Pervasive impact and consequences of fatigue on life

Fatigue has various and far-reaching impacts and consequences on people's lives and their daily functioning. The impacts are grouped into four categories: physical, cognitive, psychological / emotional or affective, and social. The summary of the categories across all three conditions is presented in Table 4-6. The most extensive descriptions of the categories are in cancer, as the data came from twelve studies. In MS and RA the impact of fatigue is covered by four and three studies respectively.

Despite the difference in the number of studies between the three conditions, there are striking similarities in terms of fatigue and its impact on people's lives. The physical impact relates predominantly to a lack of energy, weakness and loss of strength reflected across all studies. Participants had to reduce, or were no longer able to perform the same types of activities. Their 'normal' activities took much longer, required a much greater amount of energy to perform, and the recovery time was also much longer.

Table 4-6 Perceived impact of fatigue on individual's life

Cancer*	MS**	RA***
Physical functioning		
<ul style="list-style-type: none"> - decreased physical performance, inability to remain active - unusual need for rest and sleep, altered sleep patterns - alterations or loss of employment - exacerbation of other symptoms, nausea, decrease in appetite - needing help with personal hygiene, household chores - lack of energy, weakness, decreased mobility, off-balance - decrease in sexual activities 	<ul style="list-style-type: none"> - powerless to perform activities, problems walking - pain, increased spasticity, reduction in dexterity, - interrupted sleep, need for immediate rest - exacerbation of symptoms, nausea, dizziness, - having less or no energy and strength - being seen as drunk or drugged, ataxia 	<ul style="list-style-type: none"> - restricted or unable to work - need help with household activities - poor sleep quality - reduced mobility - tired during the day
Psychological/ Emotional/Affective functioning		
<ul style="list-style-type: none"> - decreased motivation, no fighting spirit, giving up - low confidence, low self-esteem, worthless, insecure, fear - frustration, anger, irritability, aggression, short tempered - anxiety, depression, mood swings, sadness, need to cry - loss of identity, grieving for the person that had been - altered and deteriorated quality of life, being out of control - self-blame, perception of shame, humiliation - stress and worry, uncertainty, unpredictability, loss of future - striving for normality, loss of life's meaning, intrusive thoughts - loss of independence, trapped, difficulty accepting assistance 	<ul style="list-style-type: none"> - having no motivation - a feeling of being absent, of being split in two parts - feeling of living a very structured life, being trapped - others did not always understand their needs - being worthless, low sense of self-worth - emotional irritability, despair, crying, sadness and sorrow - <i>'a pitiful person'</i> - perception of shame, guilt for not managing to continue with work 	<ul style="list-style-type: none"> - poor motivation - frustration, irritability, anger, rebellious - low self-esteem, useless - depression, low mood - oversensitive, stressed, unpleasant, aggressive, anxious, self-pitying, misunderstood

Cancer*	MS**	RA***
Cognitive functioning		
<ul style="list-style-type: none"> - lack of concentration, impaired memory and recall, - confusion, loss of judgement, reasoning, difficulty in problem-resolving - slow mental pace, lack of creativity - loss of 'verbal fluency', 'lost for words' 	<ul style="list-style-type: none"> - lack of concentration, poor memory, difficulty problem solving - perception of lower cognitive ability - difficulties in withstanding disturbing sound - communication impairment, slurred speech 	<ul style="list-style-type: none"> - decreased concentration
Social functioning		
<ul style="list-style-type: none"> - change or loss of roles within the family and family dynamics - deterred from social life, isolation, being left out, difficult to plan ahead - loss of former social contacts, inability to create new ones - being trapped in the sense of needing help from others - feelings of becoming a burden on those closest - fatigue makes being in company difficult 	<ul style="list-style-type: none"> - communication problems - change of roles in family, social and working life - involuntary isolation, life become boring - being mistaken by others for being drunk, some chose to stay indoors 	<ul style="list-style-type: none"> - strained roles, relationships - restricted or unable to participate in leisure activities, sport - unable to support others - life on hold, can't plan

Key: Studies reporting impact of fatigue: Cancer* - Glaus *et al* (1996), Pearce & Richardson (1996), Ream & Richardson (1997), Magnusson *et al* (1999), Lindqvist *et al* (2004), Porock & Juenger (2004), Potter (2004), Gledhill (2005), Bennett *et al* (2007), Olson *et al* (2007), Spichiger *et al* (2012); MS** - Stuifbergen & Rogers (1997), Flensner *et al* (2003), Olsson *et al* (2005), Mills & Young (2008), Blaney & Lowe-Strong (2009); RA*** - Hewlett *et al* (2005), Repping-Wuts *et al* (2008), Nikolaus *et al* (2010).

An increased need and desire for (immediate) rest and sleep were reported, with altered sleep patterns and quality of sleep affected by fatigue (Glaus *et al.* 1996, Porock & Juenger 2004, Gledhill 2005, Mills & Young 2008, Repping-Wuts *et al.* 2008). The reduction in physical strength and activity affected work by either changing or restricting working hours or people feeling unable to work. The financial implications of these changes were not discussed. In cancer and MS exacerbation of nausea, dizziness, light-headedness and loss of balance were reported (Stuifbergen & Rogers 1997, Olsson *et al.* 2005, Olson *et al.* 2007, Mills & Young 2008). This further affected people's ability to mobilise, and increased their dependence and reliance on others for help. Fatigue in cancer patients has been also reported to decrease appetite and nutritional intake, and for some led to the abandonment of treatment. A decrease in sexual activity was reported resulting in a further impact on relationships (Gledhill 2005, Hewlett *et al.* 2005, Mills & Young 2008). One study in cancer fatigue reported cardiovascular symptoms such as heart pounding and feeling out of breath (Olson *et al.* 2007).

Reduced cognitive functioning was reported across all three conditions (Table 4-6). In cancer and MS memory problems, particularly short term memory, information recall, reasoning, judgement and problem solving were frequently reported. Participants had a perception of lower cognitive ability, slower mental pace and difficulties in accomplishing meaningful tasks. Language processing problems with slurred speech, lack of verbal fluency and difficulty finding the right words '*lost for words*' (Bennett *et al.* 2007, Blaney & Lowe-Strong 2009, Pongthavornkamol *et al.* 2012), combined with poor coordination (ataxia) and unsteadiness on their feet, led to participants being seen by others as under the influence of alcohol or medication (drugs) (Olsson *et al.* 2005, Olson *et al.* 2007, Mills & Young 2008). Problems with expressing '*true meaning and feelings*' (Blaney & Lowe-Strong 2009) and having '*difficulties to respond appropriately*' (Hewlett *et al.* 2005) led to participants being unable to take part in or avoiding conversation. Additionally in one MS study '*difficulty in withstanding disturbing sound*' (Flensner *et al.* 2003), and in a cancer study '*lack of creativity*' (Gledhill 2005) were experienced because of fatigue.

Fatigue affected many aspects of participants' psychological functioning. Decreased or lack of motivation, a lack of courage, '*no fighting spirit*' (Glaus *et al.* 1996) and '*no zest for life*' (Ream & Richardson 1997) were reported in all three conditions. Negative feelings of frustration, anger, irritability and lack of patience, as well as feelings of low mood, stress, anxiety and depression were commonly experienced, which in turn led to participants

feeling emotionally exhausted (Ream & Richardson 1997, Stuifbergen & Rogers 1997, Magnusson *et al.* 1999, Lindqvist *et al.* 2004, Gledhill 2005). Fatigue impacted on people's confidence and self-esteem, leaving them feeling worthless and helpless (Magnusson *et al.* 1999, Flensner *et al.* 2003, Potter 2004, Nikolaus *et al.* 2010a), with feelings of shame, humiliation and self-blame for not being strong (Lindqvist *et al.* 2004, Gledhill 2005, Pongthavornkamol *et al.* 2012). They doubted themselves and their unreliable body, constantly moving between hope for improvement and giving up hope, feeling trapped in their failing body and grieving for the person they used to be and for the life they had enjoyed: '*Why can't I be me again?*' (Ream & Richardson 1997). Loss of roles and life's meaning, greater dependence on help from others, and feeling they had to live a very structured and restricted life, altered and reduced their current quality of life. Frequent changes in mood because of fatigue lead to participants feeling misunderstood, lonely, isolated and self-pitying. In cancer, fatigue also induced intrusive thoughts including those related to dying (Potter 2004, Gledhill 2005).

The social impact of fatigue affected personal (strain on roles and family dynamics, inability to take more active part in family and social life) and professional (cancelled events, difficult to plan ahead, becoming unreliable) relationships (Pearce & Richardson 1996, Ream & Richardson 1997, Stuifbergen & Rogers 1997, Flensner *et al.* 2003, Lindqvist *et al.* 2004, Potter 2004). Fatigue deterred people from social and pleasurable activities and led to involuntary isolation: '*life goes on without me*' (Pearce & Richardson 1996). Participants lost their former social contacts and often they were not able to create new ones. In cancer studies, participants felt as they were becoming a burden on others. There was a difficult balance to achieve between needing help and wanting to remain independent.

4.5.2.5 Theme 5 Helpful and unhelpful strategies for managing fatigue

Strategies for managing fatigue were presented in 15 papers. A range of self-care activities, both physical (e.g. rest, sleep, exercise, balanced diet) and psychological (e.g. stress reduction, positive thinking, managing negative emotions) were used (Table 4-7), however the effectiveness of the methods was reported as variable. Often participants '*didn't know what to do*' (Hewlett *et al.* 2005), and in the absence of helpful professional advice, resorted to a trial and error approach.

Table 4-7 Self-management methods to cope with fatigue

Cancer*	MS**	RA***
- reduction in activities, rest, relaxation, nap, energy conservation, pacing, reading, listening to music, sleeping pills, sexual activity were invigorating, alternative medicine	- energy conservation, do less-physically and emotionally, pacing, prioritising, help from others, work smart – maximise performance, accomplish valued activities	- making conscious decisions in life and prioritising, learning to let things go
- physical activities, attempting to improve strength and stamina through physical exercise, walking (was most frequent), planning ahead, knowing what to expect can regain sense of control, planning and preparing both physically and mentally	- enhancing resistance to fatigue, improved sense of well-being, physical activities, exercise, rhythmic aerobic to increase stamina, nutritional strategies (balanced meals, dietary supplements), listening to music, light reading, talking on the phone with friends, rest, nap and sleep	- pacing, rest, relaxation, reading, listening to music, TV, learning to appreciate the beneficial aspects of rest
- accepting fatigue, making sense, denial, avoidance of attempting to feel in control- <i>'I give in to it'</i> , struggling in vain against fatigue, strategy alternates between fighting against and accepting fatigue, be strong and go with the flow, setting achievable goals	- positive attitude, seeing fatigue as inconvenience rather than force driving one's life choices, desire for acceptance of life, focus on what one can manage instead of what they can't, concealing and coping: working behind the scenes overt/ covered strategies, use of humour	- positive attitude, acceptance, not wanting to be a complainer, try to manage fatigue alone, self-management is variable with variable success
- experiencing or lacking support, social support, emotional support, delegation, reducing frequency of going out, - support systems from health professionals, families, friends, neighbours, individual's religious power, will power	- desire for a structured daily living: advanced planning, following a rigid pattern, time to do things and time to rest, avoiding feelings of stress, doing things in advance, allocating more time so to do things in a calm way, plan what to eat to feel well	- fatigue can make daily life easier, being able to fall asleep easier, the boss can see when one is really tired and being able to use fatigue as an excuse
- informational needs met, patients received information about fatigue e.g. video, talking with the nurse /physician	- medications to promote sleep or stimulants e.g. caffeine to improve energy levels during the day, temperature control, cooling after over-heating, knowledge about disease and fatigue was helpful	- need for more information about fatigue was identified
- absence of advice from health professionals, many did not expect advice regarding fatigue, no counselling by health professional was reported	- suggestions from friends, family and others with MS – use of wheelchair to conserve energy, keeping life simple, taking acetaminophen before exercise - very few learned any practical strategies for dealing with fatigue from HCPs, even if medication for managing fatigue existed HCPs were very reluctant to prescribe it	- professional support is rare, most did not remember or did not receive professional advice, professional support was not patient-specific, and often not practical to carry out

Key: Studies reporting fatigue management strategies: Cancer*- Pears & Richardson (1996), Magnusson et al (1999), Lindqvist *et al* (2004), Porock & Juenger (2004), Potter (2004), Bennett *et al* (2007), Olson *et al* (2007), Wu & McSweeney (2007), Tsai *et al* (2010), Spichiger *et al* (2012); MS** - Stuifbergen & Rogers (1997), Flensner *et al* (2003), Mills & Young (2008), Blaney & Lowe-Strong (2009); RA*** - Hewlett *et al* (2005), Repping-Wuts *et al* (2008), Nikolaus *et al* (2010).

There were apparent similarities in the methods used to manage fatigue between cancer, MS and RA populations. Helpful (positive) and unhelpful (negative) strategies were reported. Amongst helpful strategies were those that participants approached with a positive attitude, made a conscious decision to use, and perceived the methods to be within their ability. This was illustrated by examples of taking frequent breaks, planned rest and sleep, reduced activities by prioritising, and getting enjoyment out of the opportunities and the activities performed. It was important for participants to have a sense of contentment from achieving small things to enjoy their life and to stay positive (Repping-Wuts *et al.* 2008, Blaney & Lowe-Strong 2009, Nikolaus *et al.* 2010b, Tsai *et al.* 2010). This was, however difficult to achieve as fatigue made them feel angry and frustrated. The unhelpful strategies were those that participants were pushed to do because of fatigue and depleted energy levels. This was illustrated by having to take breaks, as they were unable to continue with, or were no longer able to perform certain activities. Participants perceived their lives as restricted and boring, and felt defeated and controlled by fatigue (Flensner *et al.* 2003, Bennett *et al.* 2007). In MS studies, additional effective methods of managing fatigue were temperature control (lower temperature) and accepting help from others as a natural part of '*an extended arm and hand*' (Stuifbergen & Rogers 1997) allowing them to live more normal lives.

People were trying to be optimistic and not to lose hope for a better life, a life without fatigue, but they were also trying to be realistic about their expectations towards their '*failing unreliable body*' (Wu & McSweeney 2007). This was illustrated in the process of '*fighting against and accepting fatigue*' (Nikolaus *et al.* 2010b). The methods used to manage fatigue could be presented on a '*fighting and giving-up*' continuum (Wu & McSweeney 2007). In cancer studies participants were also prepared to '*endure fatigue*' as a price to pay for successful treatment (Spichiger *et al.* 2012).

There was disrupted unity and a constant internal battle between body and mind: '*my mind says get up and do something, and my body says, no you can't move*' (Wu & McSweeney 2007). The 'fight' and 'surrender' and the divide between 'body and mind' (body seen here as physical energy, and mind as motivation or perseverance) may further explain individuals mentally striving for control, but not having the energy to succeed. Individuals' low level of motivation and physical energy not being translated into action, results in them losing the battle against fatigue.

In the fatigued individual there was a breakdown between ‘self-body’ unity, with ‘body’ speaking an unfamiliar language not understood by ‘self’ and ‘self’ having to listen and learn to interpret the ‘body’ language (Wu & McSweeney 2007). Through being intuitive, listening to the body and achieving the balance between hope and reality, activity and rest, expectations and abilities, or achieving re-unification of ‘lived-body’ and ‘object-body’ may help to adopt a new form, a new way of being in the world.

Following the review of evidence the new synthesised understanding of the phenomenon of fatigue in (the selected) chronic conditions is summarised below:

- Fatigue is described using same or similar terms and metaphors across all three (cancer, MS and RA) conditions. Participants have difficulty to clearly explaining what fatigue is
- The experience of fatigue reported by participants reflect many similarities in terms of feelings, meaning and impact of fatigue on individuals’ lives, and confirms the multifaceted and multidimensional nature of fatigue
- Fatigue is seen as having a predominantly negative effect, diminishing or depriving individuals of enjoyment and control over their lives
- Many different factors may affect the severity of fatigue and the person’s ability to manage it. People with fatigue need advice and support taking into account their individual circumstances, including type of illness and cultural factors
- Through an individualised assessment and education about fatigue, it is important to identify positive methods of managing fatigue which would be acceptable and manageable for that individual
- The divide between ‘fight and surrender’ needs to be utilised in a positive way to help people to be in-tune with their fatigued ‘body and mind’ and to regain control over their lives
- Fatigue causes people to have to re-adjust and find a new way of being in the world by resolving the conflict between what they want to do (lived-body) and what their body is capable of (object-body).

4.5.3 Methods used to study the phenomenon of fatigue

The meta-method part of the meta-study relates to epistemological soundness of included studies. In this review it examines the appropriateness of the methodologies and methods

employed to study the phenomenon of fatigue (Paterson *et al.* 2001). Critical appraisal tools adapted from Paterson *et al.*, (2001) and CASP guidelines (Public Health Research Unit 2006) helped with the evaluation and critique, and provided a platform to validate the trustworthiness of the results in the reviewed papers. All papers were assessed by the PhD student, but to enhance the rigour of the quality appraisal eight papers were independently assessed by a second assessor (first supervisor). Both assessors confirmed most of the assessment criteria. Where opinions differed, this was resolved by discussion and mutual agreement. The possible impact of different approaches and methodologies on the studies' results were explored. In this part of the analysis similarities and differences of the philosophical underpinnings, design features, sampling techniques and approaches to data collection and analysis were scrutinised.

4.5.3.1 Quality appraisal of reviewed studies

The quality appraisal results of the reviewed studies are presented in Appendix VIII. There were 27 assessment criteria against which each study was judged (Paterson *et al.* 2001, Public Health Research Unit 2006), each criteria attracting one point if the information was provided in the paper. None of the studies met all criteria, the mean of missing scores was 4.9 (range 2-10) with 'identification of assumptions and preconceptions' and 'discussion of the time frame of data gathering' being the most frequently missing items, for 22 and 15 studies respectively. The next most frequently missing items were discussion of trustworthiness of the results and identification of study limitations, 13 and 12 respectively. A further critique of methodological design and quality is presented below.

4.5.3.2 Research design

The quality of the review papers varied in terms of their methodological strengths and limitations. All papers provided a clear statement of the study purpose, aim or research question. The majority aimed to describe, explore or gather in-depth descriptions of fatigue, or to understand the experience, manifestation, meaning, categories and dimensions of it. One study aimed to explore the underlying concepts and to clarify the definition of fatigue (Gledhill 2005), one to define the symptom of fatigue (Mills & Young 2008) and one to examine the attributions of it (Siegel *et al.* 2012). A study conducted in Canada by Olson *et al.*, (2007) employed ethnoscience method and set out to 'refine the conceptual definitions of tiredness, fatigue and exhaustion and to identify the boundaries between them' (p.E2). A study conducted in Thailand also used ethnoscience (Pongthavornkamol

et al. 2012), with the same design as Olson *et al.*, (2007), to learn ‘about the social construction of illness by comparing the meaning of fatigue’ (p.E1) between two culturally different populations. Four studies, all exploring cancer-related fatigue, used two cohorts of participants to compare the experience of fatigue between cancer and healthy individuals (Glaus *et al.* 1996, Gledhill 2005), cancer and chronic obstructive airways disease (COAD) (Ream & Richardson 1997), and cancer and CFS (Bennett *et al.* 2007).

The methodological designs of the studies were not reported by nine papers (Stuifbergen & Rogers 1997, Porock & Juenger 2004, Hewlett *et al.* 2005, Bennett *et al.* 2007, Mills & Young 2008, Repping-Wuts *et al.* 2008, Nikolaus *et al.* 2010b, Tsai *et al.* 2010, Siegel *et al.* 2012). Where a specific theoretical design was not identified, the authors just stated that a qualitative study, qualitative descriptive design or exploratory descriptive design was used. Failure to identify the specific methodological design creates additional difficulty in assessing the study quality. Three papers were defined as phenomenological, but provided insufficient detail on whether a descriptive or interpretive stance was taken. Closer inspection revealed that, of these three studies, two (Pearce & Richardson 1996, Blaney & Lowe-Strong 2009) used interpretive and one (Ream & Richardson 1997) descriptive phenomenology.

Only one study (Mills & Young 2008) used a mixed methods design and the rest were qualitative; four studies used grounded theory (Glaus *et al.* 1996, Magnusson *et al.* 1999, Gledhill 2005, Spichiger *et al.* 2012), eight phenomenology, of which five were interpretive (Pearce & Richardson 1996, Lindqvist *et al.* 2004, Potter 2004, Olsson *et al.* 2005, Blaney & Lowe-Strong 2009), two were descriptive (Ream & Richardson 1997, Flensner *et al.* 2003) and one study (Wu & McSweeney 2007) stated that they used ‘phenomenological tradition as developed by Husserl and Heidegger’ (p.118). Eight studies used an unspecified qualitative design, as presented above, and two (Olson 2007, Pongthavornkamol *et al.* 2012) used ethnoscience, a method influenced by an assumption that cultural knowledge is based on language and actions (Leininger 1985, Field & Morse 1996). All designs seemed to fit with the study purpose and the methods used. Only one study (Ream & Richardson 1997) explicitly stated their assumptions and preconceptions of the studied phenomenon.

Studies in cancer fatigue utilised the most diverse methods to study the phenomenon, with grounded theory, descriptive and interpretive phenomenology, ethnoscience and an unspecified qualitative design being used across 15 studies. In research of MS-fatigue, two studies used interpretive (Olsson *et al.* 2005, Blaney & Lowe-Strong 2009) and one

descriptive phenomenology (Flensner *et al.* 2003), one a mixed-method design (Mills & Young 2008) and one an unspecified qualitative approach (Stuifbergen & Rogers 1997). All three studies in RA-fatigue were of unspecified qualitative design. The diversity of methods used to study the phenomenon of fatigue contributed to its more extensive exploration and a richer description.

4.5.3.3 Sampling and data gathering methods

All studies included in this meta-synthesis identified a sampling procedure, however the amount of detail regarding how participants were selected varied between studies. A variety of sampling methods were used: purposive, convenience, theoretical, systematic, nonprobability and consecutive patient sampling. Information regarding sampling techniques was limited, therefore it is not always clear how a particular sampling method was used in practice e.g. systematic sampling, and not all sampling techniques were specific to qualitative research design e.g. convenience and consecutive sampling. A combination of snowball and theoretical or open sampling with a more strategic theoretical sampling as the study progressed was also used. All these sampling methods were relevant to the conceptual frameworks and/or the research purpose (Rice & Ezzy 1999). In qualitative research there is no one single strategy advocated for sampling, due to the great variety of research approaches, purposes and settings (Miles *et al.* 2013, Punch 2014).

Most papers provided inclusion criteria on the basis of which prospective participants were selected. Three studies did not state their inclusion criteria; Flensner *et al.* 's (2003) study of MS-fatigue recruited volunteers who responded to a letter distributed to a local MS group, Gledhill (2005) recruited from wards or outpatient cancer clinics, and Porock & Juenger (2004) who also researched cancer-related fatigue, only stated that 'suitable patients' (p.357) were recruited. Due to insufficient information being provided, it was impossible to judge the criteria of patients' suitability for the study. To achieve the aims of the research, it is essential that the recruited participants have the experience and are able to talk about the phenomenon under study (Creswell 2013, Silverman 2013).

A variety of different methods were used to gain access to research sites and to identify potential participants. Advertisements in local papers, notice boards and letters distributed directly to outpatients as well as personal contacts and liaison with ward and outpatient clinic staff were all utilised. In many cases (eleven studies) suitable patients were identified by, or under the direction of medical and nursing staff (Glaus *et al.* 1996, Pearce &

Richardson 1996, Ream & Richardson 1997, Magnusson *et al.* 1999, Lindqvist *et al.* 2004, Porock & Juenger 2004, Potter 2004, Bennett *et al.* 2007, Wu & McSweeney 2007, Siegel *et al.* 2012, Spichiger *et al.* 2012). The rationale behind selecting specific methods to gain access to a study population may vary, however all aimed to attract voluntary respondents with experience of the studied phenomenon to take part in the study to achieve rich and diverse data (Punch 2014). All studies except one (Hewlett *et al.* 2005) gave a description of gaining access to the research site, and all studies, except one (Pearce & Richardson 1996) described the demographic characteristics of study participants. Providing a description of participants' socio-demographic characteristics is crucial to allow readers to make connections between study findings and a specific population group.

In total 381 participants were included across all 23 studies and population sizes ranged from 4 – 40 participants. This included 224 cancer participants (population size 4 – 40), 82 MS (population size 10 – 40), and 75 RA (population size 15 – 31). Mean age ranges were reported between 44.6 and 70.2 years, and individual participants' age ranged from 20 to 90 years. This reflected the populations across disease groups. In Tsai *et al.*, (2010), where participants' mean age was 70.2 years, the study aimed to explore the experience of fatigue in older Taiwanese women with breast cancer. The majority (66.4%, N=253) of participants were female, whilst males constituted 32.5% (N=124), and in one study (Pearce & Richardson 1996) participants' gender (N=4) was not stated. Three studies, one in MS (Olsson *et al.* 2005) and two in cancer (Bennett *et al.* 2007, Tsai *et al.* 2010), only included female participants.

Data gathering methods were stated in all 23 studies and they had a good fit with the studies' designs. Thirteen used semi-structured face-to-face interviews, and only one study (Repping-Wuts *et al.* 2008) conducted interviews over the telephone. Eight studies used unstructured, open-ended or in-depth interviews, one study (Bennett *et al.* 2007) used focus groups, and one (Pongthavornkamol *et al.* 2012) reported using unstructured interviews to start with and moving to more structured as the study progressed. All interviews were audio-recorded and transcribed verbatim. All studies, except five (Stuifbergen & Rogers 1997, Porock & Juenger 2004, Olsson *et al.* 2005, Siegel *et al.* 2012, Spichiger *et al.* 2012), provided either the interview topic guides (semi-structured interviews) or described the interview process (unstructured interviews). Porock & Juenger (2004) only stated that semi-structured interviews were conducted at the patient's bedside by a research assistant and were audio-recorded and transcribed. Eight studies stated the time frame for data gathering and reported lasting 2 months (Lindqvist *et al.* 2004), 3 months (Glaus *et al.*

1996), 4 months (Wu & McSweeney 2007, Repping-Wuts *et al.* 2008), 5 months (Tsai *et al.* 2010), one year (Magnusson *et al.* 1999, Olsson *et al.* 2005) and 16 months (Siegel *et al.* 2012). Duration of interviews ranged from 20-150 minutes; most (nine studies) were reported to be between 30-60 minutes, three 65-90 minutes and three lasted over 90 minutes to up to two and half hours. Two ethnoscience studies (Olson 2007, Pongthavornkamol *et al.* 2012) conducted initial recruitment interviews of about 30 minutes duration followed by two to three main study interviews with each participant; however they did not specify the duration of the interviews.

4.5.3.4 Data analysis strategies and reporting

Researchers make their study results understandable and believable to the reader in two ways; firstly by identifying and describing the process of data analysis, and secondly by detailed reporting of the findings supported by representative quotes (Paterson *et al.* 2001).

Most of the reviewed papers used well established data analysis methods. Five studies (Glaus *et al.* 1996, Magnusson *et al.* 1999, Gledhill 2005, Bennett *et al.* 2007, Spichiger *et al.* 2012) used grounded theory and the constant comparison method and provided relevant references (Strauss 1987, Strauss & Corbin 1990, Strauss & Corbin 1998, Clarke 2005, Glaser & Strauss 2009). Thematic analysis was also used by five studies (Pearce & Richardson 1996, Ream & Richardson 1997, Flensner *et al.* 2003, Potter 2004, Spichiger *et al.* 2012) and the references underpinning the methods were provided (Giorgi 1975, Colaizzi 1978, Burnard 1991, Moustakas 1994, Karlsson 1995) by all except one study (Spichiger *et al.* 2012). Content analysis, used by four studies (Stuifbergen & Rogers 1997, Porock & Juenger 2004, Wu & McSweeney 2007, Tsai *et al.* 2010) utilised more generic references (Lincoln & Guba 1985, Berg 1998, Creswell 1998, Graneheim & Lundman 2004). Componential analysis supported by Spradley (1979) and Evanescio & Key (1975) were used by two studies (Olson 2007, Pongthavornkamol *et al.* 2012), structural analysis by Ricoeur (1976) used by two studies (Lindqvist *et al.* 2004, Olsson *et al.* 2005), and framework approach informed by Pope (2000) was used by two studies (Mills & Young 2008, Nikolaus *et al.* 2010a).

Hewlett *et al.* (2005) stated using thematic analysis and constant comparison, but cited references referring to both grounded theory and descriptive phenomenology (Colaizzi 1978, Hayes 2000, Glaser & Strauss 2009). As they did not state their study's theoretical design, except just saying that qualitative interviews were used, it is difficult to judge if the

data analysis methods fit with the methodology. Repping-Wuts *et al.*, (2008) and Blaney & Lowe-Strong (2009) stated using theoretical framework and inductive analysis respectively, but neither description of the methods or supporting references were provided. Qualitative data management software was used by three studies, two (Gledhill 2005, Bennett *et al.* 2007) used NUD*IST and one (Siegel *et al.* 2012) used ATLAS.ti.

Findings were presented in themes, subthemes and diagrams, consistent with the methodology in most of the studies. Identification of relationships between categories and themes were provided in all but three studies (Pearce & Richardson 1996, Mills & Young 2008, Siegel *et al.* 2012). The themes and the analysis were well supported by the representative quotes in all of the studies. Four studies (Glaus *et al.* 1996, Gledhill 2005, Mills & Young 2008, Repping-Wuts *et al.* 2008), apart from qualitative data, also used a component of quantitative analysis presenting percentages, histograms, counting incidents, frequencies, mean values and standard deviations. The quantitative approach to data analysis and presentation was inconsistent with the studies' designs, as only one of these was a mixed-method design (Mills & Young 2008). All main findings were extensively discussed and examined against existing literature in all studies, except two (Pearce & Richardson 1996, Wu & McSweeney 2007).

4.5.3.5 Ethical considerations and trustworthiness

With the exception of two studies (Stuifbergen & Rogers 1997, Nikolaus *et al.* 2010b), all reported gaining either written or verbal approval from ethics committees or institutional boards. Nikolaus *et al.*, (2010b) state that more information regarding their study design can be found in online supplementary material where gaining ethics approval may have been reported, however the online content could not be located. Pseudonyms were used by all studies to protect participants' anonymity. Readers and consumers of research need to be reassured that the study was conducted in an ethical way, not disclosing participants' identifiable information (Israel & Hay 2006), and this was demonstrated in the reviewed studies.

Not all authors explicitly reported on credibility, dependability, confirmability and transferability of their studies, concepts that are important to demonstrate the trustworthiness of results. However, authors often reported techniques employed to minimise study bias. Among the techniques utilised to enhance and demonstrate trustworthiness were: data saturation, prolonged engagement in data analysis, involvement

of multiple researchers, expert panel (steering group) to oversee the study, involvement of patients, member-checking, being transparent by recording significant events and process of decision making in a log book, and use of existing literature to validate the new findings. Data saturation was reported by only seven studies (Magnusson *et al.* 1999, Gledhill 2005, Hewlett *et al.* 2005, Bennett *et al.* 2007, Mills & Young 2008, Tsai *et al.* 2010, Pongthavornkamol *et al.* 2012). It is possible that data saturation was not reported, as it was not achieved. Another argument is that data saturation is impossible to achieve, as the researcher may never know what is out there to be discovered, in relation to what they found (van Manen 1997). This would indicate that fatigue needs to be further explored to gain a more comprehensive understanding of the phenomenon, but it is impossible to know everything.

4.5.3.6 Identification of limitations of studies

Study limitations were acknowledged by ten papers. Cut-off points for fatigue level (level at which fatigue was seen as problematic) used in two studies (Hewlett *et al.* 2005, Bennett *et al.* 2007) may have excluded participants with lower levels of fatigue from taking part. Fatigue at lower levels may be equally difficult to manage, have negative impact on people's lives and reduce their QoL. If only participants with higher fatigue levels are included in the study, the findings will be reflective of only that section of the population. Researcher-related bias such as professional background and preconceptions may have affected the collection and interpretation of qualitative data, but was reported by only two studies (Magnusson *et al.* 1999, Mills & Young 2008). For the study results to be seen as trustworthy all possible biases need to be identified and possible impact considered (Holloway & Wheeler 2002, Rolfe 2006).

Conducting one-off interviews was seen as a possible limitation to achieving deep understanding of the phenomenon (Magnusson *et al.* 1999, Wu & McSweeney 2007). One-off interviews may not capture full description and meaning of the studied phenomenon; however it is never possible to identify the complete 'picture' and the 'true' meaning of the experience, particularly where the horizons of that experience are ever changing. Data collected via a longitudinal study may address this issue and provide fuller understanding of the studied phenomenon. Small sample sizes (Wu & McSweeney 2007, Spichiger *et al.* 2012) and use of convenience sampling (Siegel *et al.* 2012) were reported as possible risks of under-representing certain groups of participants and resulting in not covering all the dimensions of the studied phenomenon (Magnusson *et al.* 1999, Tsai *et al.* 2010). The aim

of qualitative research is not to be representative of the entire population, but to provide a rich description and deeper understanding of the topic of study. It is impossible to uncover everything about the topic so bringing together the findings from a range of studies will address the limitations of any single study and provide synthesised evidence. Due to ever-changing horizons, there is always more that could be found out and new experiences that could be described (Moustakas 1994).

Repping-Wuts *et al.*, (2008) report their relatively large (for qualitative research) sample size (N=29) as a limitation, stating that statistical analysis and generalising may not be possible. The aim of qualitative research is not to generalise nor statistically analyse data. This type of comment relates to the quantitative rather than the qualitative paradigm and may be confusing to the reader. Other factors such as the study setting, cultural influences (Pongthavornkamol *et al.* 2012), restricted access to research site and provider bias (Siegel *et al.* 2012), not discussing the findings with participants or individuals in similar settings, and not achieving data saturation (Spichiger *et al.* 2012) were reported as hampering the transferability of the findings.

A variety of methodological aspects were utilised in the studies, creating a much broader and fuller understanding of the studied phenomenon. The quality of each study was judged on the number of missing criteria. Each study was allocated to one of three quality categories: High (1 – 3 missing criteria), Medium (4 – 6 missing criteria) and Low (7 and above) (Table 4-8).

Table 4-8 Results of quality of studies

Study quality	Number of studies	Studies
High	8	Glaus <i>et al</i> (1996); Ream & Richardson (1997); Magnusson <i>et al</i> (1999); Potter (2004); Olsson <i>et al</i> (2005); Repping-Wuts <i>et al</i> (2008); Tsai <i>et al</i> (2010); Pongthavornkamol <i>et al</i> (2012)
Medium	11	Flensner <i>et al</i> (2003); Lindquist <i>et al</i> (2004); Hewlett <i>et al</i> (2005); Bennett <i>et al</i> (2007); Olson <i>et al</i> (2007); We & McSweeney (2007); Mills & Young (2008); Blaney & Lowe-Strong (2009); Nikolaus <i>et al</i> (2010); Siegel <i>et al</i> (2012); Spichiger <i>et al</i> (2012)
Low	4	Pearce & Richardson (1996); Stuifbergen & Rogers (1997); Porock & Juenger (2004); Gledhill (2005)

There was a maximum of ten missed criteria. Studies were not excluded on the basis of quality as even lower-quality studies have the prospect of contributing information about the studied phenomenon. The literature suggests that studies of a lower quality should be given less emphasis when synthesising the results (Lloyd Jones 2004, Hannes 2011). However, comparing the findings from studies of different quality reveals similarities between studies from the three quality categories.

Drawing conclusions on the quality of the study is subjective as it is difficult to know whether the quality of the published paper or the quality of the study is being judged. The two are linked but not identical. Simply because the particular criterion is not reported in the paper does not necessarily mean that this has not been done in practice, and what can be reported is often influenced by journal requirements.

4.5.3.7 Recommendations and directions for future research

Recommendations for further research from the authors of the reviewed studies are contained in Appendix IX. Combining the findings of the reviewed studies, the following recommendations can be made:

- Based on similar language used across different studies, the multidimensional experience and impact of fatigue is similar between the three conditions (cancer, MS and RA). However, there is a degree of overlap and repetition between type, dimension and impact of fatigue. There is a need for further studies, particularly longitudinal studies, exploring phenotypes and patterns of fatigue to develop a more comprehensive understanding of the concept over time and cross-sections of population and in different conditions
- There are similarities of factors impacting on fatigue and its severity across conditions. Therefore there is a need for quantitative studies to explore the impact of clusters of factors (physical, psychological, emotional and social) on fatigue
- Fatigue is seen as having a predominantly negative effect on every aspect of people's lives. They are in a constant battle with life-restricting or limiting fatigue and have to manage on small levels of energy. Management strategies to deal with fatigue can be categorised as either constructive or non-constructive and the daily battle between 'body and mind' needs to be further explored and interventions specific to address this internal battle need to be developed and tested

- Care specific to individual needs and abilities was reported as effective and therefore healthcare practitioners need to integrate the evidence from different conditions to deliver individual-specific care.

4.5.4 Theories used to study the phenomenon of fatigue across different chronic conditions

The meta-theory part of meta-analysis explores the links between the theoretical orientation of the included studies and research results (Paterson *et al.* 2001), and it relates to both theories underpinning the study design, as well as the theories that arise from the research. Ritzer (1992) stated that meta-theory is less concerned with the research process and more with the end-product. The purpose of this meta-theory was therefore to explore the relationship between the theoretical frameworks used in the reviewed studies and the research outcomes. The influence and the relationship between the theory and newly developed knowledge will vary, depending on which theory has been used to structure the study design and to analyse data (Paterson *et al.* 2001).

Of the reviewed papers, thirteen clearly stated and some described the methodological theory guiding the study design and underpinning the data analysis (Appendix X). Four studies (Glaus *et al.* 1996, Magnusson *et al.* 1999, Gledhill 2005, Spichiger *et al.* 2012) used grounded theory with the aim of theory generation and understanding the concept of fatigue. Findings were presented in a manner consistent with the methodology: themes, figures and visual models of the interrelationships between symptoms and the evolution of fatigue. Some findings were also presented in more quantitative formats including percentages, means and pie charts; this way of presenting data is not appropriate in grounded theory.

Five interpretive phenomenological studies (Pearce & Richardson 1996, Lindqvist *et al.* 2004, Potter 2004, Olsson *et al.* 2005, Blaney & Lowe-Strong 2009) set out to explore human experience as it is lived (Merleau-Ponty & Edie 1964), or to understand the way of being in the world influenced by Ricoeur's (1976) philosophy, where the main aim is to explain and understand the meaning of phenomena. Those who utilise the philosophical approach proposed by Heidegger acknowledge that history, background and culture help participants and the researcher to make sense of experience (Koch 1999). The studies' results were presented mainly in themes and sub-themes, and one study (Potter 2004) also presented tabulated data (key themes and categories), and provided figures explaining the

interconnectedness of themes. In two studies utilising Ricoeur (1976) in data analysis, findings were presented at two levels of analysis that is, naive understanding and comprehensive understanding of the phenomenon (Lindqvist *et al.* 2004, Olsson *et al.* 2005). Descriptive phenomenology, concerned with discovering people's unique experience, was used by two studies (Ream & Richardson 1997, Flensner *et al.* 2003) and employed Moustakas' (1994) and Karlsson's (1995) methods respectively. Both methods involve two levels of data analysis. Moustakas' (1994) method requires the researcher to undertake textural (description of the phenomenon) and structural (explanation of possible relationships between different categories) analyses of the data, and both types of analysis should be done at the individual and group level. The final stage of Moustakas' analysis requires formation of a composite textural-structural description of the essence and the meaning of the experience. Karlsson (1995) also requires two levels of analysis; the noetic (individual) description, and the noematic (general meaning) of the phenomenon. Findings were presented in themes and sub-themes, but Ream & Richardson (1997) only presented textural and not structural results.

An ethnoscience design used by two studies (Olson 2007, Pongthavornkamol *et al.* 2012) was underpinned by ethnographic theory (Spradley 1979), and the data analysis was influenced by adaptation theory (Selye 1952), on the basis of which the Fatigue Adaptation Model was developed by Canadian authors Olson *et al.*, (2007). The model was researched further in Thailand (Pongthavornkamol *et al.* 2012) to compare the similarities and in differences in describing fatigue between Thais and Canadians. This research explored the cultural, social and religious beliefs and values and their impact on describing fatigue and social construction of illness.

This meta-theory indicated that studies included in this review were influenced mainly by the methodological research design, and only one study (Olson 2007) used adaptation theory in the data analysis. The design of the reviewed studies varied and following Paterson *et al.*'s (2001) classification, could be categorised into theory generating (grounded theory), theory testing and depicting the phenomenon of fatigue (phenomenological descriptive and interpretive), theory framed (ethosscience study by Olson *et al.*, (2007) and theory evaluating (Pongthavornkamol *et al.* 2012) studies. No overarching theory of chronic disease fatigue emerged. Irrespective of which methodology was used, the findings were presented in a very similar way. This may reflect a poor execution of the methodological designs of the studies resulting in similar findings being

presented or it might mean that there are many similarities in the end-product, regardless of the methodological design of the study.

4.6 Discussion of findings from the reviewed papers

The meta-synthesis process enabled the presentation of fatigue as a subjective, multidimensional, difficult to define and hard to explain phenomenon (Glaus *et al.* 1996, Ream & Richardson 1997, Hewlett *et al.* 2005). Fatigue was presented as a process mainly described by metaphors. Chronic disease-related fatigue is much more than being tired and is more severe than that experienced by healthy individuals (Gledhill 2005). Fatigue was ever-present, debilitating, all absorbing and time-consuming, involving the whole human being (Stuifbergen & Rogers 1997, Flensner *et al.* 2003, Wu & McSweeney 2007). Participants in many studies, instead of expressing the experience of fatigue, presented the consequences of fatigue (Magnusson *et al.* 1999, Potter 2004, Olsson *et al.* 2005, Bennett *et al.* 2007). The clear distinction between tiredness, fatigue and exhaustion as proposed by Olson *et al.*, (2007), was not supported by other studies, as all the terms were used interchangeably. These findings suggest that fatigue should be seen on a single continuum of varying severity. Presenting what would appear to be a researcher-imposed division between fatigue, tiredness and exhaustion, as separate concepts may be interesting as an academic debate, but it is not helpful for recognising fatigue and delivering care in clinical practice.

Fatigue with its many dimensions (physical, cognitive and psychological) also impacts on all aspects of an individual's life and reduces their QoL. Fatigue and fatigued body and mind were experienced as a barrier to participating in the surrounding world and an enemy of survival (Olsson *et al.* 2005). Participants tried to master their fatigued body in an attempt to regain control, but often they did not have physical and/or mental energy to succeed and had to surrender. Their lives were measured by an '*I cannot*' instead of '*I can*' capacity (Wu & McSweeney 2007). Unpredictability of fatigue, lack of awareness of effective strategies to combat fatigue and an inability to be in control of their lives caused participants distress.

The meta-synthesis identified both shared and individual experiences of fatigue across the reviewed conditions. There were many more similarities than differences in sensation, trajectory, causes, consequences and strategies for managing fatigue. The differences

related to fatigue in MS which was often reported as related to being too hot, so one of the strategies to manage fatigue was to keep temperature down and to prevent the body from over-heating. In cancer, chemotherapy (amongst other factors) was almost always responsible for triggering fatigue, but being informed about fatigue during chemotherapy and knowing the cause of fatigue resulted in participants being less distressed (Siegel *et al.* 2012). Participants in cancer studies were generally better informed about the possibility of experiencing fatigue as part of the disease process, or treatment or both (Spichiger *et al.* 2012) than participants with MS or RA. In some cancer studies, the meaning of fatigue was linked with incurable illness and approaching death causing a greater level of distress (Lindqvist *et al.* 2004, Potter 2004).

Self-care strategies for managing fatigue related to energy conservation (reducing stress and physical activities, pacing, prioritising and support systems), efforts to regain energy (resting, sleeping and nutrition) and activities enhancing resistance and stamina (exercise) (Stuifbergen & Rogers 1997, Tsai *et al.* 2010). These categories are based on the strategies reported to be tried by the participants taking part in the reviewed studies. Most of the strategies for managing fatigue were inadequately described and reported variable or no benefit (Potter 2004, Hewlett *et al.* 2005). Despite the evidence (Ahlberg *et al.* 2003, Cramp & Daniel 2008) on effective strategies for managing fatigue in cancer patients there was limited evidence of patients being enabled to be self-sufficient in terms of managing fatigue.

The results synthesised in this meta-study come predominately from high and medium quality studies from a variety of designs. This review helped to better understand the phenomenon of fatigue and the extent of its impact on people's lives in chronic conditions.

4.7 Summary

This chapter has presented a range of descriptions of fatigue and the impact of fatigue on the lives of people diagnosed with cancer, MS and RA. In addition, the range of factors perceived either as triggering or aggravating fatigue were identified and compared between the conditions. There is overwhelming evidence demonstrating similarities in how fatigue is described and experienced and how it impacts on peoples' lives in these chronic conditions.

The antecedents and factors aggravating fatigue related to the disease process and its treatment, both physical and psychological, as well as factors related to everyday functioning in private, professional and social spheres of life. A range of methods to manage or to cope with fatigue were used. The difference between managing and coping related to the level of control and the utilisation of helpful (positive) and unhelpful (negative) strategies imposed by fatigue. Methods related to managing fatigue involved a greater level of planning and active decision making; in coping, the individual's role was more passive and accepting of the situation. The locus of control e.g. 'I control the fatigue', or 'the fatigue controls me' played a determining role in where on the 'fighting or giving up' continuum participants perceived themselves to be.

A need for more or better information on fatigue was identified by participants across all conditions, however HCPs either did not provide the information, or the information was not patient-centred. In some instances where participants were informed that fatigue is an integral part of their illness, they did not expect HCPs to take an active role in fatigue management and perceived fatigue as a symptom to be endured as nothing could be done.

The recommendations based on this review are that further research is needed in all three conditions, but particularly in MS and RA where limited evidence on fatigue exists. Currently-available evidence on fatigue needs to be better implemented in helping patients to manage this symptom.

Chapter 5 Methodology and methods

5.1 Introduction

The aim of the study is to explore the experience of living with fatigue as described by people diagnosed with IBD. Therefore, ‘voice’ has to be given to study participants to allow them to tell their story. A qualitative research design offers the most appropriate methodology for this purpose. This chapter outlines the process of selecting the study methodology by:

- Briefly presenting the theoretical underpinning of qualitative research
- Critiquing the qualitative methodologies (grounded theory, ethnography and phenomenology) that were considered for this study and discussion of the rationale for rejecting or accepting a particular approach
- Presenting a comprehensive exploration of phenomenology as a methodology for this study
- Providing a detailed account of the research methods used to conduct the study
- Exploring the researcher’s role during the study process and her possible influence on the results.

5.2 The theoretical underpinnings of qualitative studies

In research there is no single, accepted way of conducting studies, the method is influenced by the aims and intentions of each study. It is necessary for the researcher to clarify to the reader the theoretical underpinnings of the chosen methodology and examine these in relation to other research paradigms. The researcher needs to explain their beliefs about the social world and what can be known about it (*ontology*), and nature and ways of acquiring that knowledge (*epistemology*) (Avis 2005). The following section outlines the traditions and historical development of research paradigms and provides the rationale for the theoretical underpinning of this research project.

For a long time the positivist approach set out by Rene Descartes (1596-1650) was a leading research methodology in social inquiry (Collinson 1992, Guba & Lincoln 1994, Wolcott 1999). The main premise of epistemological knowledge was based on principles of natural

science and mathematics, advocating that studies of ‘objects of nature’, ‘natural events’ and ‘the way that objects behave’ combined with careful reasoning could form the basis of finding the ‘truth’ (Guba & Lincoln 1994). Descartes postulated that mathematical principles could be applied in studying human sciences, where the social world could be uncovered and understood as clearly and with the same level of certainty, as a mathematical equation (Descartes & Sutcliffe 1968, Guba & Lincoln 1994). According to Descartes, this type of enquiry would enable social researchers to uncover objective, valid and reliable ‘truth’ about society and everything that there is to know about the social world (Collinson 1992, Guba & Lincoln 1994, Hamilton 1994). This resulted in only observable phenomena being studied and the belief that empirical knowledge arises from the experimental methods, providing a scientific explanation of cause and effect relationships, that is value-free, reflects universal ‘truth’ and establishes laws about the natural world (Green & Thorogood 2014).

Past and present social scientists were influenced by positivist philosophy, believing that rigorous and systematic collection of social facts would enable them to build objective and bias-free understanding of the studied phenomenon (Ritzer & Goodman 1996). The post-positivist perspective, also known as critical realism, continued with this school of thought suggesting that objective truth about the social world is ‘probably possible’ to be observed and generalised to a wider population (Guba & Lincoln 1994:109). As a result, a considerable body of knowledge in social science was and still is influenced by research methods derived from natural science.

The epistemology of qualitative research developed in contrast to the positivist and post-positivist notions that all knowledge is out there to be discovered, can be manipulated, measured and easily described (experiments, surveys, observational studies), and is deductive and generalisable. The fundamental tenet underpinning qualitative epistemology is its disagreement with the existence of one correct version of reality or truth; instead, it advocates the existence of multiple versions of reality, even for the same person (Grbich 1999, Braun & Clarke 2013). As a result, approaches used in human inquiry should allow for the complex and multifaceted nature of emotional and subjective human experience to be captured and explained (Green & Thorogood 2014).

Prior to qualitative research, the view of scientific inquiry was that the mind (using the senses, usually sight and hearing, often aided by technical instruments) simply records whatever is happening in the world (Bowling 2009), but Immanuel Kant (1724-1804),

reversed this view by arguing that the mind shapes and organises sensory inputs. Kant presented and explained the process of qualitative research as a discovery of the relationship between the mind and the world, that is, between the object and the subject of the inquiry (Kant 1949). He believed in a notion rooted in the subjective experience and the relationship between the mind and the world which directly challenged the existence of objective and universal truth, pointing to its temporality and a dialectic relationship. The role of the researcher in qualitative inquiry was identified to be as important as the role of the research subjects, as it is through the researcher's perception, skills and knowledge that the world – studied phenomenon – is revealed (Guba & Lincoln 1994, Hamilton 1994).

It is this subjective premise of knowledge that the current research and its purpose is based on. It is important to identify the theoretical perspective at the stage of the study design, as this provides the framework and directs the researcher's attention in collecting and interpreting data (Punch 2014). This PhD researcher believes in the existence of 'multiple truths' of social reality or *ontology*, and that qualitative research is fundamentally based on the relationship between the researcher and the researched which helps to gain an understanding of the studied world or *epistemology*. Different methodological approaches are underpinned by different philosophical assumptions, and to determine the right methodology for the study, both elements, *ontology* and *epistemology*, need to be considered. Indeed, if qualitative research is to produce 'valid' findings, the researcher should maintain consistency between the philosophical starting point and the adopted methods (Morse 1991, Guba & Lincoln 1994).

5.3 The research aims

Qualitative research commences with a broad research aim, which guides the stages of the inquiry. The aims of this study are to explore the phenomenon of fatigue and how it affects the lives of people diagnosed with IBD. The specific study objectives are to:

1. Provide a detailed description of the phenomenon of fatigue as reported by people diagnosed with IBD
2. Explore fatigue management methods used by people with IBD
3. Identify and analyse the meaning and impact of IBD-fatigue on people's lives.

The experience of fatigue ‘as lived’ by people with IBD was the starting and end point of the research, and the researcher’s aim was to transform lived experience into (as much as possible) an exhaustive expression of its essences. Van Manen (1997) stresses the importance of keeping one’s original research question at the forefront when doing qualitative research, as only then it is possible to ask the ‘what is it like’ question in the attempt to understand the lived experience of the studied phenomenon.

5.4 Consideration of qualitative methodologies to conduct the study

There are multiple qualitative research methodologies each having their own distinctive characteristics. The most frequently used are grounded theory, ethnography and phenomenology, and all have the potential to support the ontological and epistemological position of this research and achieve the aims of this study. The methodological features and their suitability for conducting this study are therefore considered.

5.4.1 Grounded theory

Grounded theory was first developed in medical sociology with the publication of studies of dying in hospital (Glaser & Strauss 1965, Glaser *et al.* 1968). The method and process of conducting the research was first described in 1967 (Glaser & Strauss 1967) and further developed and presented in two key publications explaining methodological developments in grounded theory (Glaser 1978, Strauss 1987).

The focus of grounded theory research is initially on unravelling the elements of experience, and from these elements and their interrelationships, a theory is developed or verified that enables the researcher to understand the nature and meaning of an experience (Strauss 1987). In grounded theory, the research process involves a series of iterative steps of data collection and inductive analysis (Strauss & Corbin 1990). Through theoretical sampling and further data collection, constant comparison between findings and data continue until theoretical saturation is achieved, that is, when new data do not present any new theoretical elements, but confirm the newly created theory (Charmaz 2011).

In the 1990s, there was further development and diversification, resulting in grounded theory becoming a family of related methods (Bryant & Charmaz 2007). However, despite

the development and clarification of grounded theory, its aim remains the same, namely to generate and test new theory (Charmaz 2011).

Grounded theory can be used successfully in areas where little evidence is available and limited understanding of the phenomenon and relationships between different elements exist (Hunter *et al.* 2011). Grounded theory was considered as a possible method for this study as there is limited understanding of fatigue in IBD. However, in grounded theory the main emphasis is on theory generation, through bringing collected data to more of an abstract entity, which at the same time separates the participant from the experience shared in the interview. As the main purpose of the current research was to explore the phenomenon of IBD-fatigue as experienced by participants, and not theory building, grounded theory was rejected as an approach for conducting this study.

5.4.2 Ethnography

Ethnography is a field research method that developed in anthropology; it studies the culturally shared perceptions of people and seeks to make sense of the world in everyday life (Hammersley 1995, Hammersley & Atkinson 2007). Ethnographers collect data through prolonged participatory or non-participatory observation in a natural setting, describing, documenting and analysing a particular culture or sub-cultural group from the *native* (group under study) point of view and bringing a strong cultural lens against which data are explained (Hammersley 1995, Hammersley & Atkinson 2007). This approach can explain behaviour and its symbolic meaning within a cultural context and cultural diversity in a way that other research approaches cannot (Spradley 1979). It also helps to discover specific needs of that cultural group and helps to develop strategies of meeting these needs. In healthcare settings, ethnography can be particularly useful in the study of clinical behaviours (Schmoll 1987) and health practitioner education (Stein 1991).

As a method of discovery, ethnography explores the nature of particular social phenomena in a natural setting, working primarily with unstructured data (collected via observation and interview) and an examination of a relatively small number of people makes it particularly useful when studying concepts that are new or relatively unexplored by research. The intention of this PhD research was to study a phenomenon where relatively little is known and only a small number of participants are needed to explore the concepts in great depth. This would suggest that ethnography would be a suitable method employed in conducting this study. However, as ethnography is based on the researchers' prolonged presence in the

field under study, it would be impossible to observe participants in their natural settings (private homes) without undue intrusion in their private lives. Additionally, the aim of this study is to explore the phenomenon of fatigue as experienced by participants, and not as perceived by the researcher through observations. Therefore ethnography was seen as an unsuitable method for this study.

5.4.3 Phenomenology

Phenomenology as a philosophy and research methodology is primarily concerned with description of the phenomenon and structures and meanings of lived experience (Omery 1983). Phenomenology as a study of phenomena is concerned with the object of human experience and aims to elucidate *what* people experience (Crotty 1996:3). The aims of phenomenology are to gain detailed understanding of the nature and meaning of everyday life, and to do phenomenological research is to try and address a question ‘what something [phenomenon under study] is *really* like?’ (van Manen 1997:42). There are two main phenomenological approaches, namely descriptive phenomenology developed by Husserl, and interpretive or hermeneutic phenomenology developed by Heidegger (Walters 1995). These two approaches are now critiqued and their suitability for conducting this study is appraised.

5.4.3.1 Descriptive phenomenology

Descriptive phenomenology is ascribed to the work of Edmund Husserl (1859-1938), who emphasised returning to the ‘thing’ or phenomenon to gain its understanding. The phenomenological tradition however, pre-dates Husserl as it originates from Franz Brentano’s (1838-1917) work in descriptive psychology, presenting it as ‘an exact science’ and advocating the concept of *intentionality* (self-evidence of mental states) which ‘could yield apodictic truth, and thereby found a descriptive science of consciousness’ (Moran 2000:23). The term ‘phenomenon’ comes from Greek and it means ‘a fact or situation that exists or happens’ - *the what*; however in its philosophical sense ‘phenomenon’ is explained as ‘a thing appearing to view’ - *the how* (The Oxford English Dictionary 2012). Brentano took this *what* as the main concept to explain the origin of ‘true’ empirical knowledge. For Brentano to truly ‘know’ was to describe the *life-world* experienced by others as they bring the world to *consciousness* (Moran 2000). At the same time Brentano advocated that experience is time and context (temporality and chronology) related e.g. nothing happens in isolation.

Edmund Husserl, Brentano's student, was inspired by Brentano's theory, which provided him with impetus to develop it further. Husserl accepted that psychology should be based on empirical evidence and this could be obtained from descriptions of people's experience of their *life-world* – *the what* (ontology), but the way *how* they come to know what they know, how they perceive the experience and make sense of it (epistemology) also needs to be identified (Moran 2000). In opposition to Brentano, Husserl did not agree with the notion of temporality and he was of the belief that the investigator should not influence description of the phenomenon, but should remain objective and free from presuppositions. Husserl is seen as the 'fountainhead' of phenomenology and the phenomenological movement, as his work on descriptive phenomenology was highly influential in 20th century Europe and North America (Spiegelberg 1975).

5.4.3.2 Interpretive phenomenology

Husserl's philosophy was challenged by his student, Martin Heidegger (1889-1976), who accepted Husserl's view that understanding *lived experience* is important, but he disagreed that this can be achieved through an objective stance (van Manen 1997). Heidegger argued that *being in the world* allows for new understanding and knowledge to develop (ontology), and that the understanding (epistemology) is created by *pre-understanding* (prior experience) of the human world which influences the interpretation or hermeneutics of the new experience (Heidegger 1962). He argued that experience of phenomenon is understood in the context of prior social and cultural knowledge. The focus of interpretive or hermeneutic phenomenology is therefore on interpretation of the experience which is intrinsic to human existence (Todres & Wheeler 2001). Heidegger reasoned that in order to *know* one needs to *understand* and therefore interpretation precedes new knowledge (Heidegger 1962). Heidegger used *being* and *time* as main concepts helping to explain new experience. He argued that interpretation does not happen in isolation, but is influenced by our experience and knowledge.

The process of data collection can be simultaneous with data analysis, and the 'hermeneutic circle' develops as the researcher and researched move back and forth between significant parts of the experience and the total experience to reach a new understanding (Todres & Holloway 2004). The researcher is required to play an active role by bringing their prior experience and pre-understanding of the phenomenon under study and the world in general into the research process (van Manen 1997). The researcher helps the participants to

identify and interpret their experience, and therefore becomes an integral part of *co-constitution* of the newly created knowledge (Cohen 1987).

As a novice to the topic of fatigue, with no prior experience and only a limited understanding of IBD, the PhD researcher could not draw on *pre-understanding* in order to *co-constitute* new knowledge in relation to the studied phenomenon. It was also feared that the researcher's active involvement and simultaneous data collection and interpretation might influence and overshadow the description of the phenomenon of IBD-fatigue, and therefore interpretive phenomenology was rejected.

As the purpose of this study was to elucidate a detailed description of the phenomenon of fatigue and its structures, as reported by people diagnosed with IBD, descriptive phenomenology was selected as the most appropriate design.

5.4.4 Features of descriptive phenomenology

The German philosopher and mathematician Edmund Husserl has been widely attributed with being the founder of the phenomenological movement. His philosophical notion of developing philosophy as an objective and rigorous science was greatly influenced by his background as a mathematician (Spiegelberg 1960, Dowling 2007). Descriptive phenomenology seeks to describe *life-world* or lived experience (*lebenswelt*) from the perspective of the individual, *bracketing* the taken-for-granted researcher's assumptions and preconceptions about the experience (Husserl 1970). This makes descriptive phenomenology particularly effective at bringing to the fore the complexity of experiences of fatigue and its perceptions from the individual's perspectives to challenge conventional assumptions and meanings.

Three themes essential to Husserl's phenomenology are *intentionality*, *essences* and *phenomenological reduction*, otherwise known as bracketing or *epoché* (Spiegelberg 1960).

5.4.4.1 Intentionality

The concept of *intentionality* relates to the epistemological question of 'How do we know?' Husserl argued that *intentionality* is a fundamental structure of consciousness and in order to know, an object (in this instance fatigue) presents itself to a subject (the person experiencing it) (Spiegelberg 1982, Dowling 2007).

Husserl asserted that the concept of *intentionality* refers to the process of conscious awareness of things and directing one's mind towards that *object* (e.g. the object of the study). *Object* in this instance is not the physical but the mental image. It therefore involves each individual's participation, an active act of perceiving by engaging memory and imagination. *Intentionality* engages the individual in their interaction with the environment, other objects or other people, with the 'intentional experience' being a combination of perception of physical appearance or experience, and memory meanings – noticing that appearance or experience. An example of this is seeing a tree (a physical object with your eyes), and perceiving (verification of a mental picture) of that tree through what a tree represents to the individual in their memory (colour, shape, movement, smell, experience), giving it meaning to the individual (Spiegelberg 1960).

Husserl argued that through the rigorous examination of objects as they present in one's consciousness, a person could come to know intuitively the essence of those objects or realities (Spiegelberg 1960). Merleau-Ponty (1962) emphasised the importance of *meaning* and the fact that in order to understand the meaning it is important to describe the phenomenon. Descriptive phenomenological study therefore begins by going back 'to the thing', describing the phenomenon and its *essences* (Cohen 1987), before exploring the structures of the human experience as it is perceived by the individual being studied (Dowling 2007).

5.4.4.2 The essences of experience

The term *essence* or the *true being of a thing* is what makes a 'thing what it is – and without which it could not be what it is' (Husserl 1982, van Manen 1997) (p.10). Therefore the ontological perspective of the experience contains both outward appearance (body) and inward consciousness (mind) of the reality (Moran 2000). In the case of Spiegelberg's (1960) example of a tree, the essence of what makes a tree is based on memory, image, and meaning of what it is to the individual.

Capturing the essences of lived experience requires the researcher to notice the 'everydayness' of that experience, the taken-for-granted things that people tend not to notice (Jennings 1986, Cohen & Omery 1994). The researcher therefore must capture and describe as closely as possible the true essence of the experience from the perspective of study participants (van Manen 1997). In the instance of the phenomenon of IBD-fatigue, it

is important for the researcher to identify the essences of that experience: what it is, and what it means to the participants.

5.4.4.3 Phenomenological reduction

The pivotal concept in Husserl's philosophy is that of *phenomenological reduction*, a procedure which uses *bracketing*. The process of *bracketing* requires the researcher to attempt to suspend all judgments about the world with the purpose of reducing bias and improving the credibility of the research (Koch 1995, McLaughlin Gray 1997). Husserl argued that this suspension, putting personal ideas and prior influences aside, was necessary if a rigorous foundation for the human sciences and fresh knowledge was to be established (Husserl 1962).

Bracketing as a term was borrowed by Husserl from mathematics. In mathematics, the use of bracketing is instrumental in carrying out complex mathematical calculations. The process involves calculation inside the bracket, before proceeding to calculate the function outside the bracket. As a process in qualitative research it should literally separate or 'bracket out' all prior perceptions in an attempt to uncover the essence of the phenomenon under study, a state of *epoché* (Crotty 1996). It is important to analyse the practical issues of *phenomenological reduction* in the process of doing research and whether, and to what extent, it is possible for a researcher to *bracket* their prejudgements and pre-understanding.

An attempt to use the strategy of *bracketing* in social science creates challenges and has been questioned by a number of researchers and philosophers (Paley 1996, Paley 1997, Lowes & Prowse 2001). A key question is whether the researcher, and indeed the participant, can ever be totally free of prior knowledge, experience, understanding and point of view (LeVasseur 2003). Merleau-Ponty (1964) argues the impossibility of complete suspension, as the researcher's pre-understanding is engaged 'in the world', and as such is a perpetual process which cannot be overcome.

The exact description of how the process of bracketing should be executed was not explained by Husserl or by other authors who reviewed the philosophical roots of descriptive phenomenology (Spiegelberg 1982). Despite the strong criticism of *bracketing*, whether it is metaphysically possible to *bracket out* prior knowledge and experience (Giorgi 1997, LeVasseur 2003), it continues to be cited as an important method of reducing bias in social research (Koch 1995, Polit & Hungler 1999, Norlyk & Harder 2010).

This PhD researcher believes that knowledge exists through a person's experience, but is not always consciously perceived by the experiencing person (ontology). The starting point for the researcher to gain understanding or developing new knowledge is through providing the participant with a voice (epistemology) to communicate their experience, which leads to a rich description of the phenomenon, its structure and the meaning that the participant attaches to their experience. The researcher is more of a 'tool' to help the person bring the experience to consciousness.

The researcher is also of a view that *bracketing out* prior experience and knowledge is metaphysically impossible. The process of *bracketing* is therefore used here as an attempt to reduce, rather than eliminate bias. *Bracketing* is used as a tool for exploring the complexity of fatigue in an iterative approach: *bracketing out* different sections and elements of experience and exploring differing horizons of that experience. Numerous examples of how *bracketing* was used in this study are presented through the process of the data analysis in Chapter 6.

5.4.5 Critique of phenomenological studies in healthcare research

Descriptive phenomenology has been widely accepted by nursing researchers as an important research method to explore and understand human experience (Boyd & Munhall 1993, Denzin & Lincoln 1998, Norwood 2000). However, nursing researchers have been criticised for an over-reliance on secondary sources which may account for a lack of understanding of phenomenology as intended by Husserl (Paley 1997). In order to overcome this, Bradbury-Jones et al., (2009) called for researchers to use primary sources to understand phenomenology and not to rely on secondary literature.

In a systematic review, considerable variations across phenomenological nursing studies have been identified, including vagueness in the explanation of terminology, and a lack of clarity and inconsistency in its application (Norlyk & Harder 2010). Health science researchers frequently claim to use a phenomenological approach, but often fail to clarify the philosophical underpinnings of the research, claiming to 'lay aside' their pre-conceptions without clearly stating why and how it was done (Lowes & Prowse 2001). Not being able to trace the relationship between philosophy and methods affects the reader's ability to assess the trustworthiness of the work.

Part of the problem may relate to the language of phenomenology – referred to as a 'polysyllabic tongue twister' (Spiegelberg 1975, p.14) . Husserl's German background and

style of writing have contributed to the challenges of understanding his language and its meaning. His writings are frequently impenetrable and even for German speakers are difficult to understand (McConnell-Henry *et al.* 2009). Husserl frequently used everyday words in ways that are alien to their common meaning. This has led to translation difficulties and has been compounded by the fact that the many of his reflections on phenomenology are still in a handwritten and shorthand state.

To adopt phenomenology for conducting research is challenging, not least due to the fact that the phenomenological language used may result in variations in interpreting the concepts. However the criticism of nurse researchers misinterpreting original phenomenological philosophy, and misrepresenting the legacy of Husserl's ideas (Paley 1997), can be counter-argued by the view that it is the researcher's responsibility to decide on 'how philosophic ideas are put into action' (Drew 2001, p.16). It could be argued that this vagueness of terminology gives the researcher freedom to interpret and adapt the methodology to the requirements of their study.

To analyse the inconsistencies of using descriptive phenomenology, a mini-review of studies underpinned by Husserl's philosophy was undertaken. The purpose of this exercise was not to comprehensively review all the previous studies undertaken in the area of patients' experience, but to learn how descriptive phenomenology was used in selected studies. The identification of phenomenological studies was assisted by searching two databases (CINAHL and PsycInfo) where nursing qualitative research papers were most likely to be published. Eleven papers were reviewed (Appendix XI).

The challenges specific to descriptive phenomenology were predominantly related to the process of bracketing and keeping an open and sensitive mind. Most authors identified bracketing as a requirement and a challenge in using phenomenology; however only some proposed a solution to the challenge. Pears & Richardson (1996) Flensner *et al.*, (2003) and Jonsson *et al.*, (2011) constantly returned to the raw data, allowing them to keep 'an open and sensitive mind' and 'to achieve the sense of the whole'. Gibson *et al.*, (2005) state that they 'carefully followed the process of *epoché* and returned to the identified preconceptions (no preconceptions stated) as each individual transcript was analysed'.

Herlin & Wann-Hansson (2010) state that to minimise the influence of the researcher (a ward nurse) conducting the interviews, they withdrew from working directly with participants (in-patients) for the duration of the study, the study participants were selected

by a third person, and a second author read and verified the analysed data. They also state that the researchers' prior experience may have a positive influence on understanding the lived experience of this population. Liu *et al.*, (2010) conducted a 'very limited literature review on the study topic to suspend their preoccupied beliefs'. Only Ream & Richardson (1997) provide a list of five preconceptions identified prior to the commencement of the study; however it is not clear how these preconceptions were handled during the process of the collection and the analysis of the data. The authors of the reviewed studies all reported the use of bracketing, but each used bracketing differently and the impact on the study results has not been clearly stated.

5.5 The research process

This descriptive phenomenological study seeks to explore the lived experience of fatigue in people diagnosed with IBD. It is crucial to select the most appropriate method guided by the chosen philosophy that will fulfil the aims of the study and to make the decision-making process clear to the reader (Marcus 1998). The best method to gain a 'thick description' of the studied phenomenon (Geertz 1973, Holliday 2007) is to talk with people; unstructured or semi-structured interviews are both considered appropriate (Silverman 2000). Qualitative research generally follows a non-linear, iterative but nonetheless organised pattern (Lewis 2003, Holloway & Wheeler 2013).

5.5.1 Gaining access to study participants

Selecting study sites and population is crucial to achieving the aims of the study (Snape & Spencer 2003). Identifying and developing a good relationship with gatekeepers may help with finding and accessing study participants. However, gatekeepers are not neutral to the research setting and gaining access through a gatekeeper may influence participants' perception of the researcher's role (Sharkey & Aggergaard Larsen 2005).

For this study, access to participants was facilitated through an existing relationship with Crohn's and Colitis UK. With a national database of over 30,000 members, this charity provides information and support to people who have CD or UC, their family and friends, as well as healthcare professionals. The charity has a website and provides updates through online and paper publications (<http://www.crohnsandcolitis.org.uk>). Volunteers for this study, as well as for a number of related studies being conducted by the researcher as

outlined in Chapter 1, were sought through an advertisement in the Charity's newsletter (Appendix XII).

5.5.2 Recruitment and selection of participants

Qualitative research concentrates on gaining in-depth data from small sample of participants (Baker *et al.* 2012). The researcher has to feel confident that they are selecting appropriate participants who will not only be able to provide the required information but who are also good talkers and storytellers (Rice & Ezzy 1999, Lichtman 2014). To achieve as full a description of IBD-fatigue as possible, a purposive sampling method was utilised (Tuckett 2004, Baker *et al.* 2012). Different qualitative research designs tend to prefer specific sampling methods (Creswell 1998, Mason 2002), for phenomenology a preferred sampling method is based on criterion selection to capture the variation of participants' characteristics and breadth of experience (Rice & Ezzy 1999, Green & Thorogood 2014).

Participants were selected using the following criteria: diagnosis of CD or UC, self-reported fatigue of differing severity, gender (10 male, 10 female), minimum age of 18 years (no maximum age), members of Crohn's and Colitis UK, and ability to communicate in English as there was no scope for translation (Green & Thorogood 2014). Each element of the selection criteria was decided on the basis of the aims of the study and the unexplored nature of IBD-fatigue as ascertained from previous studies (Czuber-Dochan *et al.* 2013b) and a preliminary literature review at the study design stage. A selection grid was used for stratifying the sample to ensure the range of characteristics were met (Appendix XIII).

Sample selection was challenging in view of the complex criteria and the requirement of possible participants to provide pre-selection information which has the potential for reduced participation (Snape & Spencer 2003). To achieve the desired population, over-recruitment of a magnitude of three or four times is usually required (Ritchie *et al.* 2003a). With simultaneous recruitment for a number of related studies, there was a greater choice of participants who met the selection criteria for the qualitative study.

Within three weeks of the advertisement, over six hundred people registered their interest. Those expressing an interest were supplied with a Patient Information Sheet (Appendix XIV), explaining in detail the aims of the study and what participation would entail. A form seeking additional demographic information was also enclosed (Appendix XV). A total of 262 people responded with the requested information, as follows:

- IBD diagnosis (either CD or UC)
- Age (18 years or above, with no upper age limit)
- Gender (male, female)
- Length of time since IBD diagnosis (<1 year, and >1 year)
- Severity of self-reported fatigue (on a scale of 0 – 10, where 0 = no fatigue and 10 = most severe fatigue)
- Geographical location (urban, rural, spread across the UK).

The sample size was informed by the literature on qualitative sampling, particularly the need to think critically about the parameters of the studied population (Ritchie *et al.* 2003a, Silverman 2013). A sample of 20 was deemed to be sufficient to accommodate the selection criteria and to provide an adequate breadth of data. The selected participants received the following information: confirmation of selection for the qualitative study; a further copy of the Patient Information Sheet; two copies of the consent form, one for the participant and the other returned to the researcher (Appendix XVI) and a prepaid reply envelope.

Within two weeks of letters being sent, 19 participants returned their signed consent form. One non-respondent, an 18 year old female, was followed up with a reminder letter. She returned the signed consent and agreed to be interviewed; however a few days before the arranged interview she withdrew from the study, stating lack of time as an explanation. She was replaced with the next youngest female, aged 21 years.

5.6 Data collection methods

Descriptive phenomenology aims to ‘give a voice’ to the study participants and the researcher’s role is to ‘capture that voice’ in the most honest and thorough way. Unstructured interviews were employed to collect the data and the researcher adopted a method of ‘saying more by letting others say it’ (Marcus 1998, p.36).

5.6.1 Unstructured interviews

Interviewing is one of the primary and most powerful methods for gathering qualitative data (Lichtman 2014). In phenomenology, interviews are the main methods of data collection (van Manen 1997) with in-depth, unstructured face-to-face interviews considered to be the best method to collect rich and detailed information regarding

participants' experience (Lichtman 2014). The unstructured nature of the interview helps the participants to spontaneously speak about their experience to uncover the feelings, experiences and words describing the phenomenon. Such interviews allow the capture of diversity among participants and capitalise on people's natural propensity for story-telling within a more relaxed conversation-like atmosphere (Grbich 1999, Kvale & Brinkmann 2009, Rubin & Rubin 2011). The unstructured nature of such interviews allows complex issues to be probed, to explore and clarify the meaning of people's experience and to enhance the researcher's understanding of that experience (Atkinson 1998, Lichtman 2014). Unstructured interviews also provide participants with an element of control over the direction and content of the conversation; they go some way to ensure that collected data is not forced or artificially constructed, for example reflecting the researcher's preconceived ideas about the concept of fatigue (Fontana & Frey 1994, Grbich 1999). However, this method sets an additional challenge for the interviewer to remain focused on the topic. This was achieved by the researcher using reflexivity to ensure that the conversation focused on the study topic. In this study reflexivity assisted in meeting this challenge.

5.6.2 Preparation for the interview

Appropriate preparation for each interview is essential as it prevents unnecessary disruption during the interview (McLellan *et al.* 2003, Turner III 2010). All participants were contacted via telephone to arrange the interview at a date, time and place convenient for them. Direct contact with the participants created an ideal opportunity for the researcher to get 'closer' to them and begin the process of establishing a rapport, minimising potential barriers to help generate meaningful and useful data and provide an opportunity for further clarification if required (Lichtman 2014). It allows for the introduction of the interviewer, further reassurance about confidentiality, explaining participant selection as well as discussing length of interview, voice-recording and note-taking (Crabtree & Miller 1999).

Only a few people asked questions about the study and what their participation would involve. Most queries related to the place of interview and whether travel was required by the participant. Additional questions may have been influenced by the anxiety to travel in relation to participants' bowel function (urgency and frequency) or their level of fatigue. Although the place of interview was clearly stated in both the invitation letter and the Patient Information Sheet; participants were further reassured that they would not be

required to travel, as the researcher would be conducting the interviews in the participant's own home, or an alternative venue convenient to the participant (Legard *et al.* 2003).

The participant's familiarity with the environment provides them with a feeling of safety and control, which may lead to good rapport with the interviewer and have a positive impact on the flow of the conversation. Seventeen interviews were arranged in people's own homes. The home environment affords an element of control in terms of privacy, access to a toilet, preventing undue stress and allowing concentration on the conversation (Elwood & Martin 2000, Legard *et al.* 2003, Lichtman 2014).

In some cases, participants wish to be interviewed away from their personal surroundings (Legard *et al.* 2003). One participant requested to be interviewed at her place of work and two participants asked to be interviewed at the university where the researcher works. The participant who wished to be interviewed at her place of work booked a meeting room during her lunch break. She was in the role of the 'host': familiar with the setting in terms of access to a toilet, and in control of the timing of the interview, which was limited by the duration of her lunch break (approximately one hour). The two interviews at the university took place in a small meeting room booked for that purpose. Participants were made to feel at ease by being provided with a drink, shown the location of toilets and encouraged to take a break at any time if required.

Interviews were recorded, as this allowed an accurate capture of data and enabled the researcher to give their whole attention to the participant and the content of the interview (Crabtree & Miller 1999, Legard *et al.* 2003, Silverman 2013). All participants were previously informed that interviews would be voice-recorded, and additional verbal consent was sought immediately before commencement of the interviews; all participants agreed.

The voice recorder was checked to be in good working order with spare batteries (Crabtree & Miller 1999). It was located in an unobtrusive place in the interview room in the researcher's line of sight to allow the device to be checked during the duration of the interview (Lichtman 2014). Positioning of the voice recorder is important, both for the quality of the recording, and so as not to intimidate the participant: they showed no sign of 'stage fright' during the interview (Legard *et al.* 2003). Strategies to put the participant at ease were utilised, including an introductory 'chat', use of open questioning, showing

interest and attention to responses, and using appropriate body language such as eye-contact or nodding (Legard *et al.* 2003, Lichtman 2014).

The researcher's safety is of paramount importance when conducting fieldwork, particularly when working alone (Lewis 2003). As much of the fieldwork was conducted in participants' own homes, appropriate arrangements needed to be made to minimise risks. These included making adequate travel arrangements (this was particularly important where more than one interview was conducted on the same day), ensuring that the researcher's plans (location, timing, duration of interview) were shared with the research secretary and that the researcher was contactable by telephone.

5.6.3 The interview process

Telephone and on-line interviews were considered as alternative methods of collecting data. These reduce the need for travel, diminish safety risks, are less time consuming and are more economic (Flick 2014, Lichtman 2014). However it was decided that, with the benefit of non-verbal communication, face-to-face contact would help establish better rapport with participants and through that, contribute to the richness of the collected data (Drew 2001, Flick 2014, Lichtman 2014).

It is important to inform participants of the approximate duration of interview as this was courteous and allowed them to plan their day (Lichtman 2014). Generally, interviews should not last longer than one hour (Field & Morse 1996); the duration of these interviews was estimated at 45-60 minutes. However it was not planned to follow this rigidly, as fatigue may not allow participants to continue beyond a certain length of time. Equally, it was imperative for participants to have sufficient time to talk about their experience (Holloway & Fulbrook 2001, Todres & Holloway 2004, Holloway & Wheeler 2013).

With all participants, the researcher sought to create a relaxed atmosphere by having a general 'chitchat' about their daily life, introducing a more conversational style of communication. The aims of the study were also reiterated and the participants were reassured that they could pause or terminate the interview at any time. Researchers recommend a warm-up period as a strategy to establish a good rapport and familiarity between the interviewer and the interviewee (Grbich 1999, Green & Thorogood 2014). Before the commencement of any questions or dialogue, the researcher checked whether the participants had any questions that arose from previous communication or about the interview process itself. It was reiterated that despite signing a consent form, participants

still had a choice to decline the interview at this stage (Fontana & Frey 1994). None declined to be interviewed.

The interviews commenced with two opening questions. The aim of these questions was to encourage interviewees to focus their attention to the topic of the study and to raise issues that were most relevant to them, also known as ground mapping and content mapping (Legard *et al.* 2003). The questions were:

1. Ground mapping question: *'Please tell me your experience of living with Crohn's or colitis'* (depending on the participants' diagnosis), and
2. Content mapping question: *'Please tell me about your experience of living with IBD-fatigue'*.

The intention of the first question was to focus the participant's mind on the topic of their condition and their experience related to the diagnosis of CD or UC. This also created an opportunity to set a background in which their experience of fatigue would be embedded. The second question took the participant directly to the topic of the study, their experience of fatigue in IBD. By using attentive listening, follow-on questions were extracted from the content of the interview and became more focused, searching for more description and better explanations of different feelings as the interview progressed. This technique was selected to help to create an in-depth understanding from the individual's perspective. Legard *et al.*, (2003) suggest there are various types of content mapping questions, such as ground mapping, dimension mapping and perspective-widening questions. Due to the complex nature of fatigue, different types of questioning encouraged participants to uncover different aspects and greater richness of the concept.

A reflective style of questioning was used to elicit more detailed information from participants to gain a fuller description of their fatigue. Examples of reflective and paraphrasing questions are:

1. *'You have said that fatigue makes you feel angry. Can you tell me more about that?'*
2. *'So what did your consultant say when you said you are tired all the time?'*
3. *'How did that make you feel?'*
4. *'What do you mean when you say that you feel like a zombie?'*

There have been debates about how active or passive the interviewer should be during in-depth interviews and how much of the agenda and content of the interview is set by the researcher and how much by participants (Holloway & Fulbrook 2001, Legard *et al.* 2003). Any research starts with a predetermined question or topic of interest. In this descriptive phenomenological study the researcher started with the topic of IBD-fatigue in an attempt to identify and reveal the essences and meaning of the IBD-fatigue experience. The detailed description of the essences of the experience and the order in which they were talked about were left in the participants' control.

The researcher was sensitive to the participant's energy levels. If participants had problems expressing their thoughts or if the researcher noticed signs of tiredness e.g. yawning or rubbing their eyes, they were asked whether they would like to stop and have a break or to terminate the interview altogether. In doing so, the researcher confirmed that participants had choice and control over the interview process and 'process consent' was gained, that is, an active ongoing permission to continue with the process of data collection (Grbich 1999, O'Leary 2004). Only a few participants took up the offer to have a 'toilet break', the majority were happy to continue with the interview with no breaks. None of the participants terminated the interview before they felt that they communicated their story.

If the flow of the conversation dried up, the researcher referred to notes taken during the conversation to regain the flow (Silverman 2014). Through the entire length of the interview the researcher used attentive listening skills, and a non-judgemental attitude (Rice & Ezzy 1999). Attentive listening skills helped the researcher to concentrate on the topic raised by the participant and ask further clarifying or expanding questions. The non-judgemental attitude helped participants to feel accepted and stimulated further conversation.

5.6.4 Finishing the interview

The researcher's decision to bring the interview to a conclusion was based on cues taken from observing the participant's level of engagement and length of answers provided, indicating their level of energy and ability to concentrate (Silverman 2014). Before finishing the interview, the participant was asked whether they would like to talk about any other issues related to fatigue. On occasion, this question stimulated the conversation for a few more minutes, before finishing the interview, at which point the voice recorder was switched off. The researcher reiterated that all the information would be kept confidential

and no identifiable information would be used in the dissemination process. At this point, demographic and disease activity data were collected (Appendix XVII) and participants were thanked for giving their time and sharing their experience.

Whilst the interview was unlikely to pose physical harm to the participant, it was possible that speaking about the experience of IBD-fatigue could evoke negative and embarrassing feelings. Participants were asked whether any part of the interview made them uncomfortable, and if they wished to add or remove any information. The researcher checked whether participants wished to contact their General Practitioner or Crohn's and Colitis UK helpline. All confirmed that they were 'happy' with the content and process of the interview. Although a number of participants were upset and appeared distressed during the interview, they explained that they cried because, through this conversation, they realised how much fatigue affected their lives. For most, this was the first time that they had the opportunity to speak with someone who was interested and listened and accepted their experience. Several participants thanked the researcher for undertaking the study, as it gave them hope and a sense of progress towards a better understanding of fatigue. Following the interviews, the researcher received a number of thank-you cards and emails from participants for providing an opportunity to talk about their experience and acknowledging the fact that fatigue is real.

5.6.5 Field notes

Field notes are the written accounts of the researcher's thoughts and observations that cannot be recorded on tape during the interview (Rice & Ezzy 1999, Bluff 2005, Ezzy 2010, Holloway & Wheeler 2013), a combination of the researcher's personal reflections as well as detailed descriptions of the event and the setting of the interview (Holloway & Wheeler 2013). It is important to start writing field notes as soon as possible after an interview, as the significance of certain information may only become apparent at a later stage of the study (Wolcott 2002).

The field notes for this study proved to be an invaluable source of reference during interview and at the data analysis stage, where complex and interweaving concepts could be compared to the researcher's earlier thoughts and descriptions. After leaving the field, the researcher reflected on each interview and made additional comments on what went well, participant's behaviour and any other issues that may have impacted on the process of the interview and the collected data, e.g. presence of other members of their family at

home or interruptions. The researcher included her feelings and reflections related to the content and the process of interview, covering aspects such as establishing rapport and the relationship with the participant (Appendix XVIII).

5.6.6 Data saturation

Data saturation is defined as ‘a state where no new data of importance to the study emerge and when the elements of all categories are accounted for’ (Cutcliffe & McKenna 2004, Rice & Ezzy 2005, Green & Thorogood 2014). In qualitative research it is generally suggested that the researcher continues to collect data until data saturation is achieved (Grbich 1999, Miles *et al.* 2013, Tobin & Stout 2015). The concept of saturation is associated with grounded theory (Strauss & Corbin 1990). In grounded theory and ethnography, where data analysis is simultaneous with data collection, it may be easier to identify the point when data saturation is achieved (Strauss & Corbin 1990, Miles *et al.* 2013).

Achieving the components of data saturation, where no new ideas arise, all categories are fully accounted for and relationships established and tested in a range of groups and settings is much more challenging than Strauss and Corbin (1990) imply. This process is potentially limitless as new information can always be presented by a different participant. In descriptive phenomenology data analysis is postponed until data are collected (van Manen 1997), therefore description of the phenomenon rather than data saturation is the aim. As data collection in phenomenology is not theory driven, themes and categories are determined at the stage of data analysis.

The literature review of sample size in relation to data saturation in qualitative studies suggested sample sizes from a few to up to 50 participants, however the conclusion was as many as you need to, to answer the research question (Baker *et al.* 2012). The main principle used in this study to determine the sample size is information richness and as exhaustive as possible description of IBD-fatigue (thick description of the studied phenomenon). The sample size for this study was 20 participants. The researcher was satisfied with the depth and breadth of the data collected and the description of the phenomenon.

5.7 Quality in qualitative research

Healthcare research receives considerable attention from the public and governing bodies in the ways in which the research is regulated and undertaken. The UK's Research Governance Framework outlines the responsibilities of all stakeholders involved in health and social care research (Department of Health 2001, Department of Health 2005). The primary purpose of the framework is to improve scientific quality and safeguard the public through promoting good practice.

5.7.1 Ethical considerations

The study fulfilled the principles of the Research Governance Framework and was approved by the King's College London Ethics Research Committee (Appendix XIX) and supported by Crohn's and Colitis UK charity (Appendix XX). Ethical issues however do not just relate to the planning of the study, but are pertinent to every stage to the research process (planning, execution of the study and its dissemination) and have been discussed in each of the respective sections of the thesis (Tobin & Begley 2004, Walsh & Downe 2006). The researcher's capability in conducting the research study was demonstrated by extensive research knowledge (teaching research methods and completion of advanced research methods modules as part of this PhD programme) and prior experience of successfully completing research studies. Registration with the Nursing and Midwifery Council since 1990 demonstrates the researcher's professional integrity and capability.

Participants were provided with a written explanation of the study (Patient Information Sheet, Appendix XIV) within the appropriate timescale governed by ethical and professional rules to allow for informed consent to take place (Crabtree & Miller 1999, Rice & Ezzy 1999, Department of Health 2001, Department of Health 2005).

In accordance with the Data Protection Act (1998), all personal information was kept confidential and participants are referred to by pseudonyms throughout the study. As interviews were face-to-face, achieving anonymity was not possible, although participants were reassured at various stages that all identifiable information will be kept confidential. It was made clear to all the participants that the researcher's supervisors would have full access to all the data and that direct quotes from the interview will be presented in the thesis and in other reports and presentations. Interview recordings were transferred onto a password-protected personal computer and all hard copies of participants' information was kept in locked cabinet in the researcher's office.

Researchers must assess the study benefits against any potential risk involved (Polit & Beck 2006, Polit & Beck 2009). Whilst there were no direct risks to participants, talking about their individual experience may have been unpleasant at times. Contact details of the Crohn's and Colitis UK helpline were included in the Patient Information Sheet, and at the end of each interview an opportunity was provided for debriefing and clarification of issues if required.

5.7.2 Trustworthiness in qualitative research

The concept of trustworthiness (or rigour) is an essential and integral part of any research and helps to ensure the methodological and ethical soundness of the research and its quality (Beck *et al.* 1994, Gough & Finlay 2003, Graneheim & Lundman 2004, Finlay 2006a). In qualitative research, rigour refers not to rigid adherence to rules and procedures, but to the methodology and methods chosen for conducting the study. The researcher needs to clearly and visibly demonstrate the process and the rationale behind the decision-making, and how the study results were derived, to make the process auditable to the reader (Fade 2003, Rolfe 2006, Finlay 2006b, Holloway & Wheeler 2013).

The four concepts related to trustworthiness are: **dependability**, **credibility**, **transferability** and **confirmability** (Lincoln *et al.* 2011). The purpose of striving for trustworthiness is to clearly demonstrate the process of designing and conducting the study to evidence that the study findings are the outcomes of the raw data and they “truly” reflect the content and context presented by the participants.

There is a body of evidence suggesting that if those four requirements are followed, the research should produce valid and trustworthy results and the process should be transparent and open to scrutiny and assessment by others. This would allow them to make their own judgement and decision about the quality of the research outcomes (Creswell & Miller 2000, Barbour & Barbour 2003, Graneheim & Lundman 2004, Koch 2006, Rolfe 2006, Bradbury-Jones 2007). Several strategies have been suggested for enhancing and demonstrating trustworthiness of the study and its results, examples being: audit trail, prolonged engagement in the field, member checking, peer review, triangulation, thick description, negative case analysis and reflexivity, amongst others (Sandelowski 1993, Koch 1995, Barbour 2001, Caelli 2001, Anastas 2004, Rolfe 2006).

Transferability or generalisability can be enhanced thorough description of the process, context and assumptions. The use of one or more of the aforementioned strategies does not

guarantee trustworthiness of the study. For example, describing the process of decision-making does not mean that the decisions were correct in the first place (Cutcliffe & McKenna 2004, Koch 2006, Morse *et al.* 2008). The PhD researcher has tried to clearly demonstrate trustworthiness with a significant amount of detail at each stage of the research process from design to its completion. The decision of trustworthiness of that process and the outcomes of that research has to be judged by the reader.

5.7.3 Reflexivity and reflection

Reflexivity is a process of thoughtful, conscious self-awareness (Mays & Pope 2000, Cutcliffe & McKenna 2004, Johnson & Waterfield 2004, Finlay 2006a), a tool which helps the researcher to be constantly aware of their own presence, and the possible impact of that presence on participant and environment.

Descriptive phenomenology requires the researcher to acknowledge their pre-assumptions and pre-understanding of the studied phenomenon. The PhD researcher identified the following pre-assumptions:

- Fatigue causes considerable problems to people diagnosed with IBD (from a focus group study)
- People who took part in focus group interviews had difficulty describing fatigue
- People reported that their complaints of fatigue were frequently ignored by HCPs
- The purpose of research is to identify existing ‘truth’ and to serve the general good of people – making lives of others better.

Whilst Husserl’s *epoché* or freedom from presupposition is difficult, or impossible to achieve, reflexivity offers the possibility of bringing pre-suppositions to consciousness and allows for an examination of the level of impact on the situation as it unfolds in front of the researcher’s eyes (Finlay 2006c, Dowling 2007).

In the process of reflexivity, the PhD researcher was constantly adjusting her behaviour, for example, by the type of questioning or offering breaks to participants in order to benefit the research process (O'Connor 2011). The researcher kept a reflective journal which helped the process of interview preparation, recording thoughts after the interview, and referring to those thoughts and feelings at the time of data analysis as a way of controlling for biases and consequently to improve the study’s rigour (Finlay 2006c, Creswell & Plano Clark 2007).

It is important, through reflexivity, to acknowledge the possible biases present at any given time. However, in a qualitative study it is impossible to truly assess the relationship between cause and effect between the pre-suppositions and the direction of the interview (Onwuegbuzie & Leech 2007). This is reflected in the example in Box 5-1.

Box 5-1 Example of researcher's use of reflexivity and reflexive thoughts

Fiona, CD, FL9: *If I'm doing something, it helps to keep me going, I mean I love to sew, and if I try if I'm feeling really tired to either get up and do something, or sew or keep going or go out or something, it's when I've finished doing all that it's like, or if I don't catch it in time and I'm just sat watching something on the telly or the news or something, and then I'll, it catches up with me when I stop [pause].*

WCD: At this point I was aware of the possibility of impacting on the direction of the conversation by asking a particular question. I could think of a number of possible questions: to ask Fiona to elaborate on the information she provided, or to ask about the type of activities that she gets involved in when she gets more tired. This would mean that I am using my own interpretation that people change the type of activities they get involved in; depending on the level of fatigue and energy they have at any given time. I could have asked what types of activities help her to stay more awake; again this question would mean that I think there are activities that may help people to stay more awake, or make them more tired. To have a continuation of Fiona's topic the question that I asked was:

WCD: *When you say it 'catches up' with you, what happens then?*

This question helped obtain additional description of the process of behaviour of this participant when she gets more tired. By asking this particular question, I used reflective questioning, as the question clearly incorporates terms and language used by Fiona.

Fiona, CD, FL9: *When that's when I kind of feel so heavy and my eyes start to get heavy and it just all comes over me, my arms feel heavy, my legs feel heavy, I can't move, all I can do is literally go to sleep. And then if I'm not feeling too bad I try and keep myself awake, and try and fight it, but I don't very often win, I always end up asleep, closing my eyes, and I try to wake up again, and then when I fall asleep I wake up and think, damn it! I was watching that, or I was doing this and I missed whatever's going on because I've fallen asleep again.*

WCD: Fiona's reply related to the description of the feeling of fatigue, methods used to stay awake, feelings related to not being able to 'fight it' and not being able to get on with her life. This example clearly demonstrates that the researcher actively listened to the participant. By using my reflexive skills, I opted for the question that had least impact on the change of the direction of the conversation.

In the course of the interview, the researcher attentively listened to the description of the participant's experience and through the researcher's own life experience made sense of what has been going on, in order to ask another question and to continue with the process of collecting the description of life experience of IBD-fatigue.

The way in which the researcher has used bracketing related mostly to identifying bias that may have influenced the way of asking open questions and the way of 'seeing'. The technique of bracketing is often regarded as a way of indicating scientific rigour in phenomenological research and in the researcher's experience helped to identify and limit bias. The practical aspects of using reflexivity in data analysis are covered in Chapter 6.

Identifying and recognising pre-assumptions and biases at any stage of the research does not mean that the researcher can identify the cause-effect relationship between bias and its impact on the research process and results. By its nature, identifying causal relationship is a quantitative process which is being imposed on qualitative research. The researcher accepts that it is only possible to identify possible bias but not the extent to which it affects the research process (Morse *et al.* 2008).

5.8 Data management

5.8.1 Transcribing

There are two schools of thought relating to interview transcription. One advocates the researcher transcribing the interviews themselves, as this helps to achieve greater familiarity with the data (Flick 2014); however this approach is very time-consuming. The second approach is for the interviews to be transcribed by a professional transcriber, an approach which is more time-effective and produces better quality transcripts, but is more expensive (Flick 2014).

This study utilised the second approach, as the use of descriptive phenomenology requires the researcher to postpone data analysis until all interviews are completed (Moran 2000). The process of transcribing can be labour-intensive (Holloway & Wheeler 2010). With no experience of transcribing the researcher was also aware that this process would be prone to error. Employing a professional transcriber produced high quality transcripts. All interviews were transcribed soon after completion, allowing the checking of transcripts and the commencement of data analysis promptly after all interviews were completed. Ethical

issues relating to the transcriber accessing the content of the interview (such as confidentiality or exposure to upsetting information) were resolved by employing a professional transcriber with extensive experience of working with the faculty (Silverman 2014).

The interviews were recorded via a USB digital recorder and transcribed verbatim. The audio recordings were listened to and the transcripts were read simultaneously. This process was used to check for the completeness of transcribing, and for the researcher to familiarise herself with the data before analysis. At this stage of the study the project's Steering Group requested the recordings and the transcripts to be quality checked by the project manager. Five transcripts were randomly selected and were listened to and fully read. Only a few minor typographical errors were identified and subsequently corrected.

5.8.2 Use of computer software in qualitative data management

Qualitative, unstructured interviews provide large amounts of data, with each transcript providing hundreds of 'bites' of information (Ritchie *et al.* 2003b). The manual process of data handling is labour-intensive and time-consuming, requiring the researcher to copy the documents, cut them into small fragments, file them in folders, create cards for each concept, and stick coloured 'post-it' notes to find relationships, draw maps and so on (Richards 2015). This process can be made easier and more time-effective with the use of Computer Assisted Qualitative Data Analysis Software (CAQDAS) (Boeije 2010) which helps with data handling (coding) and management (Punch 2014). A number of packages, such as NVivo and ATLAS.ti, are specifically designed to fulfil these functions.

Some criticisms of CAQDAS in analysing qualitative data have been made. It is argued that these programmes do not allow for creativity and may only lead to generalised descriptive analysis of the studied phenomenon (Goble *et al.* 2012). However, much of this criticism has come from authors publishing in late 1990's and early 2000's, in the early years of the use of CAQDAS (Thompson & Barrett 1997, Welsh 2002). Recently produced packages are more flexible and adapted to the requirements of the qualitative analysis process (Bazeley & Jackson 2013).

These packages cannot break the transcripts into meaningful fragments or judge the value or meaning of the data (Boeije 2010). It is the researcher who is in control of the process and requires researcher proficiency in order to maximise the benefits of using the programmes (Bergin 2011). The PhD researcher completed training provided by the

University of Surrey CAQDAS centre (www.caqdas.soc.surrey.ac.uk) and has become proficient in their use.

NVivo is the most widely used software in most social science disciplines (Punch 2014). This is a qualitative data analysis package designed to organise and analyse complex non-numerical and unstructured data (Bazeley 2007). The NVivo 9 software programme was used to assist in the process of data handling, coding, generation of themes, queries, retrieving quotes for thesis preparation and providing safe data storage (Bazeley 2007). By quick and accurate search and retrieval of particular data it can add to the rigour and validity of the analysis process (Welsh 2002).

The process of data analysis was structured by the use of Moustakas' framework (Moustakas 1994). This framework consists of a series of steps, and a detailed description of each step with examples reflecting practical application is provided in Chapter 6.

5.9 Summary

This chapter presents and critically analyses the main concepts of descriptive phenomenology. The rationale for choosing descriptive phenomenology, as the method that best achieves the study aims has also been provided.

Selected published research using descriptive phenomenology has been reviewed giving the opportunity to examine how the different concepts were operationalised by other researchers, helping to understand how they went about addressing the methodological challenges. The strengths of the methodology have been evidenced and supported by the reviewed literature. This demonstrates the close match with the aims of the study, namely gaining an insight into people's experience of IBD-fatigue from their own perspective.

The methodological challenges are based predominantly around terminology. This could be viewed as a criticism of Husserl for making it over-complicated. It is however important to remember that phenomenology is a methodology and philosophy at the same time. Therefore, the terminology used may be deliberately 'vague' to allow for different interpretations and different ways of using the methodology in various areas of practice. This line of argument would support the positive aspects of phenomenology, rather than be a criticism or limitation.

Chapter 6 Process of data analysis

6.1 Introduction

The purpose of this chapter is to illustrate the process of data analysis, to provide transparency on how the final themes were created and to reassure the reader of the trustworthiness of the findings. The process of qualitative data analysis is complex, non-linear, demanding and time-consuming, requiring methodological skills and personal integrity of the researcher. This chapter therefore aims to underpin the trustworthiness of the study findings by:

- Critiquing methods of qualitative data analysis and providing the rationale for choosing Moustakas' (1994) method
- Presenting a detailed explanation of each step of the data analysis process, and
- Providing examples to demonstrate how the method has been operationalised.

The dominant features of descriptive phenomenology, as described in Chapter 5, is capturing essences, also referred to as '*the essential, invariant structure*' of a phenomenon and '*returning to the things themselves*' (Section 5.4.4), in order to generate and present the conscious perception of human experience (Koch 1995). A descriptive phenomenological study aims to present the studied phenomenon in both the textural form (what the experience looks like) and the structural form (explanation of the experience's meaning), reflecting the experience of participants taking part in the study as well as providing a composite description of the experience of the group as a whole (Moustakas 1994). Comprehensive elucidation of the research question and generation of a full description of the phenomenon under study depend on identifying and bringing together the essences of the experience through the data analysis process.

Data coding and analysis commenced after all the interviews were transcribed, and the building of themes and categories continued right through the preparation of the thesis. Interpretation of qualitative data is a complex and dynamic process, requiring creative artistry, but at the same time skills of exactitude, discipline and patience (Miller & Crabtree 1999). In order to achieve the aims of the study and follow a thorough and rigorous process, various methods of phenomenological data analysis were considered, including Colaizzi (1978), van Manen (1990) and Moustakas (1994), before the data collection took place. In

terms of specific guidance on data analysis, Colaizzi (1978), van Manen (1990) and Moustakas (1994), all suggest a stepwise process, with the aim of trying to unearth something ‘telling’ and ‘meaningful’. Although van Manen (1990) uses different terminology, his description of the process closely parallels that of Colaizzi (1978). There is agreement among the three phenomenologists cited above that a stepwise approach to analysis begins with immersion of the researcher in the participants’ narratives, and a close reading of the transcripts in order to understand the experience as a whole and to identify units of meaning. Units of meaning, also referred to as references, are the quotes that will be linked to codes created from the data.

Colaizzi (1978) and van Manen (1990) take a more composite approach to the studied phenomenon from an early stage in data analysis, whereas in Moustakas’ method data are analysed at individual level first, before composite (group) analysis is conducted. The analysis of data at the individual level allows identification of variations of fatigue experiences; whereas the aim of composite analysis is to identify similarities reflecting the group experience. Therefore, on closer examination, Moustakas’ method appeared to be the most suited to fulfil the study aims as it deals with the data at the individual as well as at the group level, providing both a description and an explanation (‘what’ - textural, and ‘why’ - structural) of the studied phenomenon (Moustakas 1994). Moustakas’ method is a modification of van Kaam’s method of phenomenological data analysis (1969) and involves a comprehensive sequence of steps to be followed (Moustakas 1994).

6.2 Moustakas’ data analysis process

A modified approach based on Moustakas’ method for data analysis was used. Moustakas’ original method of data analysis involves a seven step process (steps 1-7 in Table 6-1). The development of a composite description, bringing together the meanings and essences of the experience representing the whole group, is discussed by Moustakas outside this seven step process (Moustakas 1994). He states: ‘The final step of my phenomenological model requires an integration of the composite textural and composite structural descriptions, providing a synthesis of the meanings and essences of the experience’ (Moustakas 1994:144). This composite textural and structural description of the studied phenomenon, namely fatigue in IBD, enabled achievement of the study aims. Moustakas’ method also proved useful in demonstrating a structure for managing individual participant’s data and

integrating the parts into a whole. In other words, it provided a means of integrating individual accounts into a phenomenological account that incorporated all participants' accounts.

In order to present the whole process utilised to analyse the study data in a clear and complete way, the step required to form the composite description of the group experience was added to Moustakas' tabulated method (Table 6-1; Step 8).

Table 6-1 Moustakas' augmented method of data analysis
(Moustakas 1994, pp 120-121)

Steps of analysis	Task to be completed
Step 1	Horizontalisation - gain familiarity with data by reading, listing and preliminary grouping of the data
Step 2	Reduction and elimination – identify statements and phrases directly related to participants' expression, description and understanding of their experience, and eliminate irrelevant and repetitive statements
Step 3	Clustering and thematising the invariant constituents (different descriptions) – cluster-related statements holding similar meanings and essence into initial themes and sub-themes
Step 4	Final identification of the invariant constituents and themes - develop an understanding of the meaning of the related statements, rearrange the interview transcript according to the new structure
Step 5	Construct an individual textural description of the experience - describe the 'what' of the individual's experience
Step 6	Construct an individual structural description of the experience - describe the 'why' of the individual's experience
Step 7	Construct an individual textural-structural description of the meanings and essences of the experience
Step 8*	<i>Develop a composite description of the meanings and essences of the experience representing the group as a whole using participants' own language</i>

Key: Step 8* in *italics* represents the step added by the researcher to Moustakas' tabulated approach.

Although the method is presented as linear, the process is more iterative, moving back and forth, between data and emerging themes, at different stages. Each step of the data analysis method is described below, and an explanation (including examples) of how it was operationalised in the overall analytical process is provided.

6.2.1 Step 1 Horizontalisation

The first step involves identification of the horizons of the experience. In accordance with phenomenological principles, scientific investigation is valid when the process of investigation and knowledge derived from that process is clearly described. This enables the reader to gain detailed understanding of the meaning and essences of the experience under study (Moustakas 1994). Husserl (1970) believed that to identify the *pure experience*, oriented to *real* constituents, the investigator needs to be free from '*presuppositions of real existence*' (p. 577). Husserl referred to this freedom from presuppositions as '*epoche*' (a Greek word meaning 'to refrain from judgement'). In *epoche*, also referred to as bracketing, one sets aside prejudgements, biases and preconceived ideas about things and has an open mind (Moustakas 1994). To achieve a comprehensive analysis and description of the phenomenon, the researcher followed the process of *epoche* by not looking for any specific aspects but rather kept an open and objective mind, to be able to 'see' the description of the phenomenon as it emerged from the data. Moustakas (1994) states that *epoche* is 'rarely perfectly achieved, [but] the energy, attention, and work involved in reflection and self-dialogue, the intention that underlines the process, and the attitude and frame of reference, significantly reduces the influence of preconceived thoughts, judgements, and biases' (p. 90).

Keeping a reflective diary, deferring the literature review (Chapter 4) to the final stage of the study and prolonged engagement with the data analysis, are examples of attempts at reducing researcher bias and keeping an open and objective mind. The transcripts were read and the audio-recordings listened to simultaneously, to check for completeness and correctness, and to appraise the quality of the transcribing. Repeated reading of interview transcripts and listening to audio-recordings, as a whole or in part, allowed the researcher to familiarise herself with the data and to identify or substantiate horizons. A sample of five transcripts was also read and the recordings were listened to by a third party to validate the completeness and accuracy of the transcripts. Only a few minor typographical errors were identified but these did not change the meaning of the content. This process validated the

quality of the transcribing and reassured that the data used for analysis represented the experience as communicated by participants.

All transcripts were uploaded into NVivo 9 software programme to assist the process of data handling during the stage of generating codes and themes. The benefit of using NVivo 9 software is that it allows the researcher to arrange the data under allocated themes and codes and link these to references (data extracts), which later facilitates easy retrieval (Bazeley 2007).

By reading and re-reading the transcripts, the researcher became receptive to statements of the participants' experience and those seemingly relevant were identified and listed. This process initiated the creation of horizons of the fatigue experience. As much as possible 'the researcher inserts themselves into the other person's experience (...) the other person's world' in the attempt to describe it (Moustakas 1994, p.124). Moustakas (1994) also argues that as horizons are unlimited 'we can never exhaust completely our experience of things no matter how many times we reconsider them or view them. A new horizon arises each time that one recedes [go back or move away]. It is a never-ending process and, though we may reach a stopping point and discontinue our perception of something, the possibility for discovery is unlimited' (p.95). This means that prolonged engagement with data allows new descriptions and meanings to be discovered.

Each horizon is discovered as it appears with its distinctive characteristics. A variety of different descriptors and qualities of the experience contribute to its better understanding. At the stage of horizontalisation, each descriptor (code) should be given the same value in the process of disclosing the nature and essence of the studied phenomenon (Moustakas 1994). An example demonstrating the process of identifying horizons is provided in Box 6-1.

An inductive approach to coding (open coding) was taken. This means that all codes identified during this stage came purely from the data, and each code was given an equal value and contribution to understanding of the nature and meaning of the experience (same level coding). The same process was repeated for all the transcripts. The identified codes and related references (verbatim quotes copied from the transcripts) were stored in the NVivo 9 programme.

Box 6-1 Horizontalisation - Section of the interview with Vicky, CD, FL 8

WCD: And can you tell me about your experience of your fatigue

Vicky: It wasn't that bad initially, it's only been sort of over the last six to eight months I'd say it's been problematic, and that's, basically I'm not sure if, it's probably down to both the problems sleeping as well as just the general fatigue from the illness. Obviously I don't process food effectively as well so, obviously not getting what I need out of that. It just means that I'm physically very tired, sort of emotionally very tired, just generally it's difficult to concentrate on things for long periods, which is particularly difficult at work; I can't walk long periods anymore because of getting very tired very easily, I have to limit the activities I do and plan, because I know I'll be too tired. I have to manage my weekends quite carefully to make sure that I'm OK to work on the Monday, so I make sure I don't do too much, I don't plan too much. It's difficult to drive long journeys, I know I'll be getting tired and sore obviously from the Crohn's, so it's very difficult in that aspect and obviously that limits, like I said, I was a very physical, healthy fit person, I used to go to the gym sort of 4 to 5 times a week for a couple of hours at a time. That's completely out of the question now! You know, I don't even want to go for a walk because I'm just too tired, by the time I get home after work, I'm quite happy to just sit on the sofa and watch telly and that's quite enough, and then get an early night if possible

WCD: Tell me more about how fatigue feels to you

Vicky: It's just extreme tiredness, I just don't want to do anything, and I don't feel like I would be able to do anything. It makes you feel very, almost inadequate I suppose, because there's things you know you could do, and you should do, but you don't do because you'll just be too tired. It makes me feel like I'm kind of letting people down in my life, because there's things I would like to do with them, and obviously I'm stopping them doing things because of the way I feel in terms of my tiredness. Like I don't visit my family as much as I should, because they live quite far away, because I know that's going to be very tiring for me. You know, in terms of the kind of physical symptoms, it's kind of heavy limbs, heavy eyes, headaches as well I find I get when I'm very tired as well. Inability to focus on things for long periods, a lack of willingness to socialise because it's tiring, a lot of effort, and it kind of, it is limiting me in terms of things I want to do, because I'm worried about for example, further education, in my career, because I know it's going to be taking on more responsibility, and that in itself will make me more tired. It's kind of limiting my career options as well. And it's a good job I've changed careers recently, because in my last job I wouldn't have been able to cope, because I was standing up a lot, I was lecturing for 2 hours at a time and I wouldn't be able to do that, were I still in that job so it's very difficult in terms of considering my career options. And that's very frustrating.

Key: Highlighted parts are the horizons of the experience; CD – Crohn's disease; FL – fatigue level on the day of the interview on the scale of 0-10 with 0 = no fatigue and 10 = severe fatigue

In total, 195 codes and 4358 references (associated quotes) were created from the interviews (Table 6-2). The number of codes per transcript ranged from 39 – 88. Longer interviews did not always result in a higher number of codes, as evidenced by two participants (Andrew and Louise), but they did provide a higher number of references related to them. The higher number of codes indicates the breadth and the variety of fatigue experience, and the number of references gives examples which evidence and substantiate the experience (Saldana 2009, Schreier 2012).

Table 6-2 Textural coding of transcripts

Participants	Length of interview (min)	Nodes (codes)	References
Sophie	55:34	62	191
Andrew	65:33	39	143
William	73:25	59	200
Mark	85:26	68	199
Vicky	62:41	87	337
Catherine	76:22	69	217
Louise	27:14	51	120
Robert	64:25	50	139
Fiona	69:49	66	159
Roger	61:10	67	167
Laura	70:10	73	210
Hugh	82:15	78	247
Henry	46:53	58	155
Sue	68:53	88	326
Ruby	63:46	72	239
Alan	66:21	65	180
Harry	77:20	86	306
Sally	70:30	82	284
Julie	86:07	88	286
Gary	81:49	79	253
Total	1355:43	195	4358

Variations in the length and the richness of each interview are reflected in the number of codes (coding density) and references (quotes) derived from each transcript (Saldana 2009, Schreier 2012).

6.2.2 Step 2 Reduction and elimination

The second step of data analysis involves two tasks, phenomenological reduction and elimination. Phenomenological reduction is identifying the textural components (descriptive characteristics) of the phenomenon as well as looking for patterns and relationships between them. Elimination refers to identifying repetitive, overlapping or vague descriptions, or descriptions unrelated to the studied phenomenon and discarding them.

According to Moustakas (1994), the task of phenomenological reduction requires the researcher to engage in a prolonged and repetitious process of looking for and describing the characteristics (textural qualities) of the phenomenon. This allows different characteristics of the experience, such as positive and negative, small or large, explicit or implicit, and taking place at different timeframes, to be identified. Thus the process of phenomenological reduction requires the researcher to focus on the object of the study itself, rather than just on perceiving the experience of the phenomenon (Miller 1984). This was interpreted in this study as trying to describe what fatigue is and how it is experienced (subject of the study) by the participants (object of the study).

The process of reduction and elimination was undertaken by determining the invariant constituents (essences of the experience). Each expression of experience was tested for two aspects: first, if it contained a necessary and sufficient constituent (element) for understanding the experience, and the second, if it was possible to extract and label the expression and therefore add to the description of the horizon of the experience (Moustakas 1994).

Expressions that were vague or perceived as unrelated to the experience were coded under a heading 'Other things that people talked about'. Moustakas recommends that all vague, overlapping and repetitive phrases should be eliminated at this stage, however in light of the possibility of new horizons and meanings being discovered, no data were deleted or excluded from the analysis at this early stage. This contributed to a 'richer' description of the phenomenon, and appeared to be a more rigorous and systematic approach to the data analysis.

6.2.3 Step 3 Clustering and thematising the invariant constituents

In this step the invariant constituents of the experience (codes and references) with similar meaning were clustered into themes and sub-themes of the interviewees' experiences (Box 6-2).

Box 6-2 An example of codes and themes identification – Section of interview with Vicky

Horizons	Codes	Thematic groups
<p>Vicky: It wasn't that bad initially, it's only been sort of over the last six to eight months I'd say it's been problematic, and that's, basically I'm not sure if, it's probably down to both the problems sleeping as well as just the general fatigue from the illness. Obviously I don't process food effectively as well so, obviously not getting what I need out of that. It just means that I'm physically very tired, sort of emotionally very tired, just generally it's difficult to concentrate on things for long periods, which is particularly difficult at work; I can't walk long periods anymore because of getting very tired very easily.</p> <p>I have to limit the activities I do and plan, because I know I'll be too tired. I have to manage my weekends quite carefully to make sure that I'm OK to work on the Monday, so I make sure I don't do too much, I don't plan too much. It's difficult to drive long journeys, I know I'll be getting tired and sore obviously from the Crohn's, so it's very difficult in that aspect and obviously that limits, like I said, I was a very physical, healthy fit person, I used to go to the gym sort of 4 to 5 times a week for a couple of hours at a time. That's completely out of the question now! You know, I don't even want to go for a walk because I'm just too tired, by the time I get home after work, I'm quite happy to just sit on the sofa and watch telly and that's quite enough, and then get an early night if possible</p> <p>WCD: Tell me more about how fatigue feels to you</p> <p>Vicky: It's just extreme tiredness, I just don't want to do anything, and I don't feel like I would be able to do anything. It makes you feel very, almost inadequate I suppose, because there's things you know you could do, and you should do, but you don't do because you'll just be too tired. It makes me feel like I'm kind of letting people down in my life, because there's things I would like to do with them, and obviously I'm stopping them doing things because of the way I feel in terms of my tiredness. Like I don't visit my family as much as I should, because they live quite far away, because I know that's going to be very tiring for me. You know, in terms of the kind of physical symptoms, it's kind of heavy limbs, heavy eyes, headaches as well I find I get when I'm very tired as well. Inability to focus on things for long periods, a lack of willingness to socialise because it's tiring, a lot of effort, and it kind of, it is limiting me in terms of things I want to do, because I'm worried about for example, further education, in my career, because I know it's going to be taking on more responsibility, and that in itself will make me more tired. It's kind of limiting my career options as well. And it's a good job I've changed careers recently, because in my last job I wouldn't have been able to cope, because I was standing up a lot, I was lecturing for 2 hours at a time and I wouldn't be able to do that, were I still in that job so it's very difficult in terms of considering my career options. And that's very frustrating.</p>	<p>Length of fatigue</p> <p>Sleep</p> <p>Diet</p> <p>Physical; Emotional fatigue;</p> <p>Concentration problems</p> <p>Work; physical activities;</p> <p>Planning; prioritising</p> <p>Driving problems</p> <p>Hobby, exercise</p> <p>Exercise</p> <p>Physical activity</p> <p>General attitude</p> <p>Sleep</p> <p>How fatigue feels/patient with CD</p> <p>Physical activity</p> <p>Attitude</p> <p>Guilt of letting people down</p> <p>Relationship family & friends</p> <p>How fatigue feels/which part of the body</p> <p>Concentration problems</p> <p>Social life</p> <p>Further education</p> <p>Career</p> <p>Work</p> <p>Frustration</p>	<p>Types of fatigue</p> <p>Factors associated with fatigue</p> <p>Types of fatigue</p> <p>Effects of fatigue</p> <p>Ways of dealing with fatigue</p> <p>Effects of fatigue</p> <p>Effects of fatigue</p> <p>Effects of fatigue</p> <p>Effects of fatigue</p> <p>Ways of dealing with fatigue</p> <p>Fatigue description</p> <p>Impact of fatigue</p> <p>Effects of fatigue</p> <p>Effects of fatigue</p> <p>Fatigue description</p> <p>Effects of fatigue</p> <p>Effects of fatigue</p> <p>Effects of fatigue</p> <p>Effects of fatigue</p> <p>Effects of fatigue</p>

At this stage of the analysis all codes were printed out and cut into strips. All the strips were arranged into preliminary themes and sub-themes on flipchart paper and displayed on a wall (Figure 6-1). The decision was made to conduct code clustering (creation of themes and sub-themes) outside NVivo 9 as this gave an opportunity to see all the data at once, allowing for more creative work to take place in terms of grouping and re-grouping the codes in the process of creating themes. Discussions with the supervisors and colleagues, and further re-reading of data linked with the codes allocated to a particular theme or sub-theme, resulted in some of the codes being moved to a different theme or sub-theme with a better fit. This iterative process of constant comparison of codes and themes with the original transcripts demonstrated the process of phenomenological reduction, helped to identify the description and meaning of the invariant constituents, enabled reflection and further refinement and clustering of the themes and sub-themes.



Figure 6-1 Creation of themes and sub-themes using the wall display

Only after being fully satisfied with the created main themes and textural sub-themes (Table 6-3), and the allocated codes, were data reorganised into the new structure in NVivo 9.

Table 6-3 Main themes and textural sub-themes

Themes	Textural sub-themes
Phenomenon of fatigue	Language of fatigue Characteristics and dimensions of fatigue Types of fatigue Fatigue versus 'normal' tiredness
Perceived contributors to fatigue	Physical contributors Psychological contributors Cognitive contributors Situational contributors
Methods of managing fatigue	Physical methods Psychological methods Cognitive methods Situational methods
Impact of fatigue	Physical impact Psychological and emotional impact Cognitive impact Social impact
Living with fatigue	As I was before fatigue As I am now How much have I lost

6.2.4 Step 4 Final identification of the invariant constituents and themes

The use of reflection and imaginative variation guided the final identification and validation of the invariant constituents (codes) and themes. Imaginative variation, employed to identify and confirm the meaning of the phenomenon, involved creative thinking and imagination, varying the frames of reference, polarities (considering diametrically opposed views or characteristics e.g. newly diagnosed versus diagnosed for a long time) and reversals (exploring the meaning in the opposite direction e.g. role of rest as a method of managing fatigue versus rest as decreased mobility and contributing to fatigue). This was done by re-reading the sets of data for different codes and re-examining their meaning and fit within the allocated themes, and using an iterative process of comparing different perspectives, functions (e.g. depression seen as a contributor to and outcome of fatigue) and relationships (direct, indirect, or no relationship between different constituents) within

the data (Moustakas 1994). Moustakas (1994) suggests that when considering the description of the phenomenon, a set of basic questions need to be answered:

1. What is the nature of the phenomenon?
2. What are its qualities?
3. What appears at different times and under varying conditions?

This stage of data analysis was performed utilising NVivo 9. This was achieved by ‘running a query’ for each individual participant and creating a report of all the codes and themes identified (Figure 6-2). This process allowed for checking of the invariant constituents – codes and the themes created – against the original interview data to make sure the themes were explicit and represented the data collected.

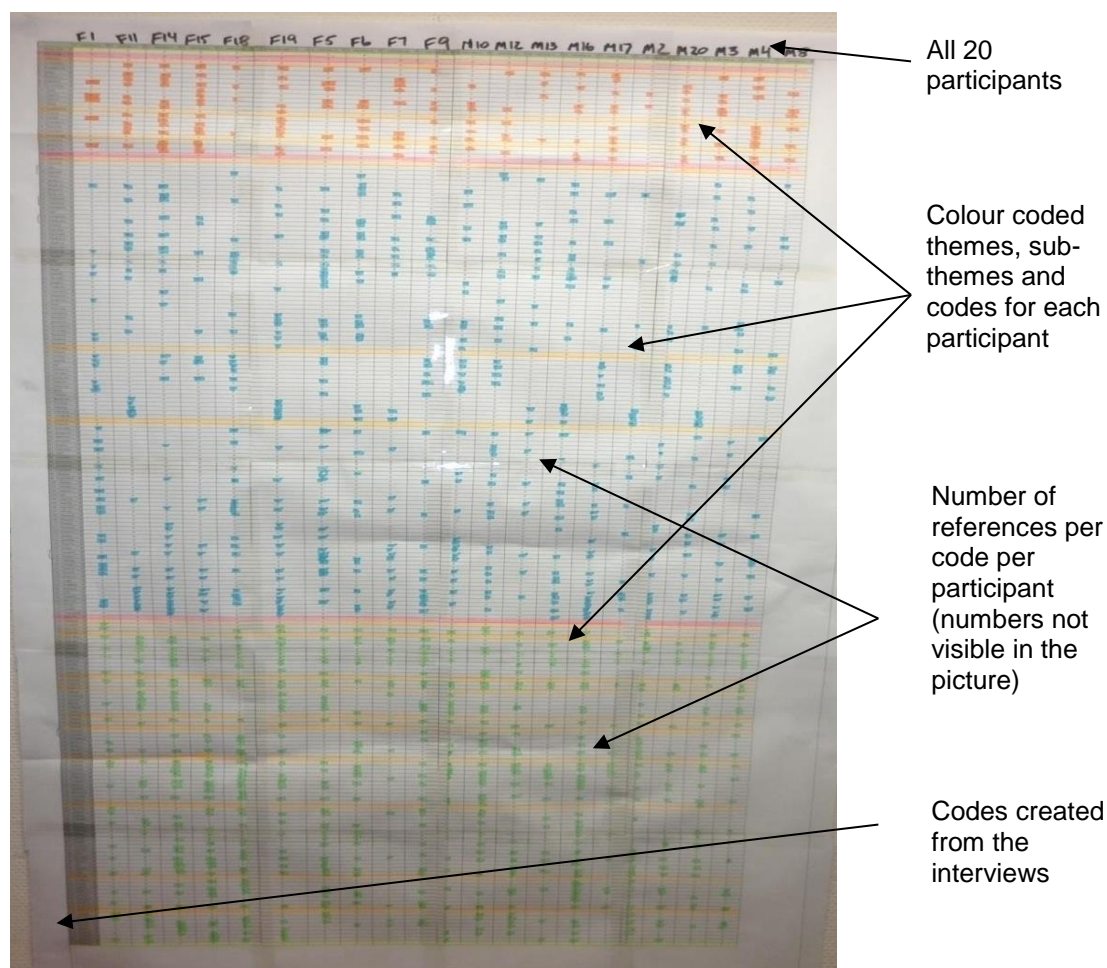


Figure 6-2 List of themes, sub-themes, codes and references for all participants – demonstrating density of coding for all participants.

The data for each individual participant were then re-arranged (using a Word document) according to the themes and sub-themes created. This recursive process was used to check how many codes and sub-categories for each theme were represented in each individual transcript.

The chart (Figure 6-2) was of A0 size, and provided a visual representation of all the themes and codes (colour coded on the chart) for all 20 participants, allowing an understanding at a glance of how many codes came from each individual transcript and how well the codes were represented across all 20 transcripts. The chart demonstrates the spread of codes across all transcripts and it was easy to identify which codes came from which participants and how extensively an individual participant talked about a specific issue (code). This was reflected by the number of references per code (data presented on the chart; however, numbers are not visible due to the small scale of the picture). The data allocated to each code were re-read and any repetition or data which were irrelevant or vague were excluded from further analysis.

6.2.5 Step 5 Construct an individual textural description of the experience

In descriptive phenomenology, description is the primary method of presenting the experience under study. This step of data analysis aimed to determine the textural components of the experience, the '*what*' of the studied phenomenon (Moustakas 1994). 'It is this '*what*' that must be explicated texturally in order to arrive at the noematic phases (process of describing) and the full noema (description of the phenomenon) as it is given' (Moustakas 1994:78). The term was originally presented by Husserl, but there is disagreement in the literature about what he meant or did not mean by the term or the nature of the noema (Moustakas 1994). One explanation is that noema is a concept, an abstract entity, detached from the object itself, while the opposite explanation is that noema is a perception attached to the studied object (Moustakas 1994). There is however agreement that the noema has two components; one that is common to all acts (an act could be a process of judging or perceiving), and another that has different characteristics (Follesdal 1982). Therefore each component of noema was judged on how similar or different they were (e.g. descriptions of fatigue experienced by individual persons). Husserl himself tried to illustrate the phenomenon of human experience by comparing it to an image of an object, where 'the object is not actually given, wholly and entirely as that which it itself is' (Husserl 1970, p.712). For example a picture of a house 'is only given from the front or the side ... but the object, as it is itself is not wholly different from the object realized, however

imperfectly, in the percept' (p.713). Hence, the individual textural description of the experience describes its feel and appearance, as well as those things that give it its typical and distinctive character (also referred to by Moustakas as invariant constituents). In the instance of the house, the typical distinctive characteristics would be the roof, the walls, door and windows. In the instance of fatigue it would be characteristics such as types, severity and pattern. From the invariant constituents and the themes of each participant's transcript an *individual textural description* of the experience was constructed. Through the researcher undertaking imaginative variation to glean the description of the phenomenon of fatigue, there was a constant process of 'looking and seeing' from different angles and with openness, over an extended period of time – allowing 'what is there to linger' to be discovered (Moustakas 1994, p.86).

At this stage a description of the phenomenon of fatigue was constructed for each individual (see Box 6-3 for an example). Moustakas (1994) provides examples of individual textural descriptions, some written in the first person and some in the third person. In order to achieve a cohesive description of the experience with a good flow, the narratives are presented in the third person with extensive use of verbatim quotes (in italics) to tell the participant's story.

Box 6-3 Individual textural description of Sophie's fatigue (CD, FL 6)

Sophie believes that her fatigue started before she was diagnosed with IBD, although it is difficult for her to *'remember when it was [that] the fatigue started'* and it is difficult to *'quantify'* how long she has been fatigued. She says *'at least 2 years, that's roughly how long since they diagnosed the IBD that I felt that I need to get something sorted here, there's something wrong.'* Sophie doesn't *'recall being [fatigued] when [she] got diagnosed entirely'*. She says *'I probably was still tired, but I think it's sort of come on gradually from there basically, because of the fight that my body's having with itself - that's what's causing the fatigue really.'*

Sophie finds the feeling of fatigue *'difficult to put into words'*. Sophie's fatigue feels as being *'absolutely knackered,'* with her *'legs and joints feeling like lead'*. It's like *'trying to run uphill, actually fighting [my] head to try and get it to work'*. *'The brain fog'* leaves her feeling as *'on autopilot'*. She feels like she *'never slept'* and she finds it is *'very hard to wake up and get going in the morning.'* She generally feels *'quite fuzzy [and] lousy'* and like she is *'pulling [herself] through porridge'*. She says *'well my normal analogy is you're swimming through treacle, just everything is a struggle to move, to do anything, to think, you know, just to breathe'*

sometimes, that you think how am I managing to do this?'. She compares her feeling of fatigue to that of when her parents died, as she has 'little interest in anything because [she hasn't] got the energy to do anything'. Sophie says 'When I had bereavement counselling a while ago, when I think about it, the brain fog I have some days is like it was after my Mum and Dad died, and it's just the comparator of it is quite scary really.' She doesn't want to be on 'autopilot' and to constantly go 'through the motions, that [she is] having to do stuff, rather than [she] want[s] to do stuff.'

Sophie's fatigue in terms of its severity and pattern changes from one day to another and also *'several times during the day'*. Sophie has a full time office-based job, and during the interview she put a lot of emphasis on her work. She uses her work and the type of activities that she can get involved in on any particular day, as a measure of the severity of her fatigue. She says *'On a bad day, I'll go home and think what have I done? I can't think I've done anything today. I mean some days I'm on the phone more than doing the work cupboard, if you just got a few pieces of paper to say I phoned such and such and discussed this, then it can seem that you haven't done a right lot of anything. But even on the days when I have got a lot of work done, I'm thinking, what did I do today? Where's it gone? You know, and my head just won't connect with the work that I've done. And so yeah, that's hard.'* She also finds that *'first thing in the morning, [she] can't take [things] in ... just cannot take it in at all.'* Reading a book is easier, because *'that's sort of like a way to getting [her] imagination firing, but [she] can't read anything serious, and likewise these days in the evening [she] can't [read] either. It's only sort of at dinner time that [she] could possibly read ... because obviously at dinner time [she's] probably have hit [her] most active in that sort of way.'* *'On a good day'* the majority of the work that Sophie does is to do with clients, as she is able to concentrate and hold a conversation. In terms of admin work *'on a good day' [she] can fly through loads ... and [she] really feel[s] on the ball, focused, and can get loads done, and [she is] really, really impressed with how the day's gone.'* This gives her a sense of achievement and satisfaction.

Sophie also talks about the pattern of fatigue during the week. She says *'Mondays are the worst for me, I know a lot of people will say that, whether it's because I have a lie-in on a Sunday I'm not sure, I really, really struggle to get going on a Monday. It sort of then slowly gets better as the week goes on and like most offices ours is quite lightweight on a Friday, people laughing and joking more than normal, so that keeps you sort of awake and alert. I can always tell how tired I must be because of the amount of Coke I drink, because that keeps me going massively. ... I start feeling normal-ish come Wednesday, and it doesn't seem to matter if I've been on holiday, if I've been doing nothing at the weekend, whatever it is, that Monday is always bad.'*

Sophie identified two types of fatigue mental and physical. She thinks that *'physical fatigue is affected by the mental'*, but she finds that *'mental [fatigue] is the worst'*, as it is an ongoing

struggle with herself and her brain. *'My brain is saying, no I don't want to move, I'm happy here, no don't want to move - too much energy. That's the ongoing struggle, which gets me down. ... I was thinking come on give me a break, somebody. And so that's another reason why it's mental rather than the physical because I'm struggling with all the stuff inside my head as well.'*

Fatigue impacts on Sophie's mental functioning, memory and her ability to focus. She finds it difficult to *'concentrate these days and focus on what [she is] supposed to be doing'* and it affects her *'speed of work'* and she *'slow[s] down'*. Things become *'a blur'* as she has no *'mental energy'*, and to help herself out *'quite often first thing in the morning [she] will do things like filing that don't really take a lot of concentration, so that [she] know[s] that when [her] brain's in gear [she] will be able to get out there and do what [she] need[s] to do, the more complex parts of the work, but even so, it doesn't always work'*. When Sophie is not *'in the best frame of mind ... [she] go[es] and do[es] something away from [her] desk ... to get moving that way'*. The sedentary activities *'like sitting in front of a computer'* put her *'brain ... half asleep'* and she finds *'difficult to think what [she is] doing'*. Sophie says, *'If I didn't have the fatigue, I reckon I could cope fine. I do, honestly, because if I didn't have that dragging me down I believe that my head would work a lot better'*. When she is fatigued, she makes mistakes at work, and she finds this very annoying and frustrating that her *'brain shuts down ... and her head won't connect with the work that [she has] done'*. She often questions herself, *'why have I typed that wrong, what exactly was my head going through? It might even not be the same letters and the word that I was trying to type. You can kind of understand in a way if it's the same letters mixed up, but I come out with gobbledy-gook'*.

Despite the fact that Sophie was diagnosed with Crohn's disease since *'a relatively short period of time'* she finds *'hard to remember how [she] was beforehand'*. She sees herself as this *'knackered'* and *'forgetful'* person with *'short memory'* and lack of *'motivation'*. She says *'I want to lose weight, I haven't got any motivation to do it and I cannot get the drive up to do it. One, because I'm just so knackered that I don't feel I can exercise ... [also] I've got all these aches and pains all over my body so I don't feel I can exercise. ... I'm not even getting off the bus early these days to walk in [to work], because I used to. And because I'm on the low residue diet, I can't eat healthy so I can't lose weight that way either. And yet it's not bothering me – it does every so often, my brain pokes me, and thinks, you should be doing something about this'*.

Things that she would normally find annoying like making *'little mistakes'*, now she doesn't have the energy to be annoyed about *'little things'*. She says *'You cannot trust yourself. No! That's a really deep part of it actually. I think I've done the job right, and I was told ages ago that basically I shouldn't keep double and treble checking myself but sometimes I think maybe I*

should. ... Sometimes when I'm doing my filing and I've already sorted it out the day before if say for instance, I was having a bit of a bad day and I've sorted things out and totally they're all gobbledy-gook, and I don't know, what? Or I've put things in the wrong place and I file them. What have I put that there for? I know it doesn't go there! But I seriously can't remember having done it'. She finds things more 'frustrating', as she is not able to be the person that she wants to be. Despite that she remains philosophical and says 'You've just got to carry on with life, and do what you can with it, we only have one of them'.

Sophie finds living with fatigue difficult and it 'grinds' her down. She has never been a morning person, but now her 'husband gets [her] up in the morning' and often she feels as she hasn't slept. She 'prise[s] [herself] out of bed, roll[s] into the shower' and doesn't 'really wake up at all until around 9 o'clock if [she is] lucky'. She constantly feels 'like putting [her] head down and going to sleep', and she often 'yawn[s in the] middle of the day'. She feels that she just plods 'from day to day' and despite her feeling that she needs to 'be doing more' she 'hasn't got the energy'. She says, 'If I didn't have the fatigue, I reckon I could cope fine'.

Work wise, Sophie thought that she would not be 'doing any more different' than she is doing now, if she did not have IBD and fatigue. She says 'administration is what I've done, practically most of my working life. I have been typing since I was 14, learnt at school, and I've always been very, very happy with typing should I say, I enjoy doing what I do, I take a lot of pride in putting things out properly. I'm making myself go forward for opportunities within the organisation and this is the first organisation there have been opportunities. Just recently I applied for a XX position. ... I had to weigh it up thinking, this isn't a good time of year for me, winter is really bad for me because I've got the fatigue twice fold, sod it, I'm going for it anyway. Because this opportunity might not come up again, if I don't get it, I don't get it, I'll know, and if I could get it this time, then I'm obviously doing something right because I'm fighting it. As it turned out I didn't get it, but I was a very strong candidate and, they told me to apply next time. I'll apply next time. It's things like that you're thinking, right, I've just got to do this anyway'. Although she does 'love the job, sometimes it gets a bit boring', and she needs 'something new to do, and [she is] looking at progressing within the company to doing a different job'. Depending on which job she will do, 'one of them could involve more driving', and Sophie is just hoping that by that time, she 'won't feel so fatigued all the time and that [she] will be able to concentrate better'. She says 'these days when I'm driving I don't feel safe, because of the people out on the road, and because I'm not sure of my concentration level and it does worry me. ... I mean I don't want to be on autopilot'.

In terms of Sophie's current role, she 'didn't go on the stage 2 training course because it was winter, and because [she] thought, [that she] can't take this in'. She is planning to go on the course 'probably in the New Year when [she] come[s] back out of it a little bit, or [she] might

leave it till the middle of the year but, [she] want[s] to then go on a college course'. She says 'I have some good days, I have bad days and my employer is fully aware of my condition and they're very supportive, so I can't fault them on that at all'.

Sophie has never taken any days off 'because of fatigue'. She says 'that's the thing about the job, I've always been motivated to come to work, if I didn't have that motivation I can well understand that I'd have taken sick days'. Later on she adds 'I could probably easily claim benefits, but I'm not going to because I want to keep working, and I would vegetate if I sat at home, and I enjoy being around people, I enjoy being able to help people. And it [staying at home] wouldn't do me any good long term'.

In terms of social life, Sophie can count her friends 'on one hand' but she has 'always struggled to let people in'. She relies mainly on her husband, her brother and one friend with whom she speaks 'every so often on the phone'. Sophie's colleagues at work are very supportive and understanding and they know that she suffers from fatigue, and they have stopped asking her why she won't go out, because they know that she is 'worn out basically'. Hobby wise, Sophie plays 'computer online role-playing games', so she gets 'to chat to people on there, but it's usually about the game'. She says 'it's nice but it's not real human contact'. Recently she got an SLR camera, as she 'loves taking photos', but she cannot read and take in the photography magazine she 'started buying to get more hints and tips on how to use a camera to its best'. Sophie has 'got loads of books at home that [she] want[s] to read and [she] just never think[s] to read them', which she finds 'frustrating as well'. Sophie doesn't go out much at all, as it 'doesn't always work on the days that [she has] got off that [she] actually feel[s] like going out and doing stuff'. She says 'you know, just have to take the rough with the smooth in that respect. Or just decide right, I'm going to push it, I'm going to go, regardless of how I feel'.

Sophie works with medical professionals and she says that 'they fully understand the Crohn's and that I may be feeling woozy because I've had such and such tablets, they'll know exactly where I'm coming from! So it's quite useful in that respect, and they've been massively supportive, I couldn't have done it without them. ... Sometimes I am going through a rough patch and I just tell them, and they say, that's fine, the workload might not go down, but they're not quite as pushy for it. ... And they read me anyway they don't even have to ask, they just know that I'm not feeling right, so they're gentle with me. ... I cannot think of a better place that I could possibly work at of all the places I've ever worked. I am in absolutely, employment wise, the best place. ... It makes a hell of a difference to know that your employer understands and respects your situation basically, it's good'.

6.2.6 Step 6 Construct an individual structural description of the experience

Until this point the focus of analysis was textural – the **description** of the phenomenon. Step 6 requires a change of focus with the analyst looking for structural description – the **meaning** of the experience. An *individual structural description* of the experience was constructed for each participant based on their individual textural description, and imaginative variation. The individual structural description provides ‘vivid accounts of the underlying dynamics of the experience, the themes and qualities that account for *‘how’* feelings and thoughts connected with the experience are aroused’ (Moustakas 1994, p.135). Structures underline textures and are inherent in them. The structural description involves conscious acts of thinking and judging, imagining and recollecting in order to arrive at core structural meanings. Texture and structure are in a continuous relationship, and ‘it is impossible to describe texture without implicit notions of structure’ (Keen 1975, p.58). Moustakas (1994) explains that ‘the relationship of texture and structure is not that of object and subject or concrete and abstract but of the appearance and the hidden coming together to create a fullness in understanding the essences of a phenomenon or experience’ (p.79). The relationship between texture and structure is not hierarchical, but the process rather requires the analyst to look through a different ‘lens’ or to take a different ‘angle’ to the analysis to provide the explanatory information. This ‘interlocking of texture and structure does not preclude the researcher from the possibility of focusing on one or the other at any given stage of phenomenological work’ (Keen 1975, p.59).

As in the previous stages, imaginative variation was employed to identify possible underlying structures that account for an experience being what it is for each individual (Moustakas 1994). This stage of the data analysis aims to answer the question ‘How did the experience of the phenomenon come to be what it is?’ The essential structures (structural coding) of the experience of fatigue were identified, providing the meaning and the explanation of the experience itself. During this process, the data were searched for information that would provide an answer to one or both of these questions: ‘What does it mean?’ - looking for a cause-effect relationship between units of data and ‘How does it make them feel?’ - looking for explanation and the extent of the impact of fatigue.

This stage of data analysis was handled by transferring the newly created textural descriptions of fatigue for all participants to NVivo 9 and conducting a second stage (structural) coding (the first stage was textural coding). On completion of Step 6, there were

45 structural codes and 2879 references reflecting the experience of all 20 participants (Table 6-4).

Table 6-4 Structural coding of transcripts

Participants	Length of interview (min)	Nodes (codes)	References
Sophie	55:34	28	129
Andrew	65:33	28	98
William	73:25	28	171
Mark	85:26	33	168
Vicky	62:41	36	220
Catherine	76:22	28	155
Louise	27:14	28	91
Robert	64:25	25	87
Fiona	69:49	34	139
Roger	61:10	32	140
Laura	70:10	33	183
Hugh	82:15	35	183
Henry	46:53	31	96
Sue	68:53	34	169
Ruby	63:46	32	156
Alan	66:21	28	102
Harry	77:20	31	191
Sally	70:30	33	131
Julie	86:07	30	144
Gary	81:49	27	126
Total	1355:43	45	2879

Structural coding of the textual description is demonstrated in a short extract from Sophie's transcript (Box 6-4).

Box 6-4 Extract from textural description of Sophie's fatigue (CD, FL 6)

Horizons	Structural codes	Structural sub-themes
<p>Sophie believes that her fatigue started before she was diagnosed with IBD, [s1] although it was difficult for her to 'remember when it was [that] the fatigue started' [s2] and it is difficult to 'quantify' how long she has been fatigued. She says 'at least 2 years, that's roughly how long since they diagnosed the IBD that I felt that I need to get something sorted here, there's something wrong.' Sophie doesn't 'recall being [fatigued] when [she] got diagnosed entirely'. [s3] She says 'I probably was still tired, but I think it's sort of come on gradually from there basically, [s4] because of the fight that my body's having with itself - that's what's causing the fatigue really.' [s5]</p> <p>Sophie finds the feeling of fatigue 'difficult to put into words'. [s6] Sophie's fatigue feels as being 'absolutely knackered,' [s7] with her 'legs and joints feeling like lead'. It's like 'trying to run uphill, actually fighting [her] head to try and get it to work'. 'The brain fog' [s8] leaves her feeling as 'on autopilot'. [s9] She feels like she 'never slept' and she finds it is 'very hard to wake up and get going in the morning. [s10] She generally feels 'quite fuzzy [and] lousy' and like she is 'pulling [herself] through porridge'. She says 'well my normal analogy is you're swimming through treacle [s11], just everything is a struggle to move, to do anything, to think, you know, just to breathe sometimes, that you think how am I managing to do this?'. [s12] She compares her feeling of fatigue to that of when her parents died, as she has 'little interest in anything because [she hasn't] got the energy to do anything'. Sophie says 'When I had bereavement counselling a while ago, when I think about it, the brain fog [s13] I have some days is like it was after my Mum and Dad died, and it's just the comparator of it is quite scary really.' [s14] She doesn't want to be on 'autopilot' and to constantly go 'through the motions, that [she is] having to do stuff, rather than [she] want[s] to do stuff.' [s15]</p> <p>Sophie's fatigue in terms of its severity and pattern changes from one day to another and also 'several times during the day'. [s16] Sophie has a full time office-based job, and during the interview she put a lot of emphasis on her work. She uses her work and the type of activities that she can get involved in on any particular day, as a measure of the severity of her fatigue. She says 'On a bad day, I'll go home and think what have I done? I can't think I've done anything today. I mean some days I'm on the phone more than doing the work cupboard, if you just got a few pieces of paper to say I phoned such and such and discussed this, then it can seem that you haven't done a right lot of anything. [s17]</p>	<p>[s1] Making sense, cause-effect attributes [s2] Phenomenon of fatigue [s3] Phenomenon of fatigue insidious [s4] Phenomenon of fatigue, fluctuating [s5] Making sense, cause effect-attributes [s6] Explaining fatigue [s7] Severity described by action [s8] Language, metaphors [s9] Living with fatigue [s10] Severity described by action [s11] Explaining fatigue [s12] Severity described by action [s13] Impact of fatigue [s14] Making sense, fatigue and emotions [s15] Motivation [s16] Changes in pattern [s17] Severity of fatigue described by action</p>	<p>1. Temporal features of fatigue 2. Invisible 3. Temporal features of fatigue 4. Temporal features of fatigue 5. Contributors to fatigue 6. Language, similes, metaphors 7. Language, similes 8. Language structure 9. Out of control 10. Language structure 11. Language, metaphors; 12. Body and mind 13. Fatigue limits me 14. Cause-effect relationship 15. Fatigue changes me 16. Fluctuating, unpredictable 17. Negative perspective, fatigue limits me, changes me</p>

Moustakas (1994) stated that the structural description of the phenomenon reveals the meaning within its description. Therefore, the structural codes were grouped into sub-themes and linked with already established themes and textural sub-themes (presented earlier in Table 6-3) of the experience of fatigue (Table 6-5).

Table 6-5 Main themes and sub-themes

Main themes	Textural sub-themes	Structural sub-themes
Phenomenon of fatigue	1. Language of fatigue 2. Characteristics and dimensions of fatigue 3. Types of fatigue 4. Fatigue versus 'normal' tiredness	1. Temporal features of fatigue 2. Metaphors, similes and language structures 3. Invisible, fluctuating and unpredictable nature of fatigue 4. Fatigue as imbalance of body and mind functioning
Perceived contributors to fatigue	1. Physical contributors 2. Psychological contributors 3. Cognitive contributors 4. Situational contributors	1. Awareness and knowledge of fatigue contributors 2. Causal relationships between contributors and fatigue
Methods of managing fatigue	1. Physical methods 2. Psychological methods 3. Cognitive methods 4. Situational methods	1. I don't know what to do and how long for 2. Positive and negative coping strategies
Impact of fatigue	1. Physical impact 2. Psychological and emotional impact 3. Cognitive impact 4. Social impact	1. Fatigue limits me 2. Fatigue stops me 3. Fatigue changes me
Living with fatigue	1. As I was before fatigue 2. As I am now 3. How much have I lost	1. Old before time 2. Being in and out of control 3. Trying to preserve sense of normality 4. New fatigued me

6.2.7 Step 7 Construction of an individual textural-structural description of the meaning and essences of the experience

A *textural-structural description* of the essences (texture) and the meanings (structure) of fatigue experience for each participant was constructed. An example is provided in Box 6-5.

Box 6-5 Individual textural-structural description of fatigue for Sophie (CD, FL 6)

Sophie has difficulty finding the right language to describe her experience of fatigue and so found it *'difficult to put into words'*. For Sophie fatigue is invisible and difficult to *'quantify'*, which is why she is not clear when her fatigue started. It *'crept on'* slowly over a period of time, before she realised that there is *'something wrong there'*. Sophie, when attempting to describe fatigue, uses metaphors. She is *'absolutely knackered'* and her *'legs and joints feeling like lead'*. Her normal daily activities make her feel like she is *'trying to run uphill [and] pulling [herself] through porridge'*. Often she finds it difficult to wake up in the morning and feels like she hasn't slept. This in turn gives her the feeling of *'the brain fog and fuzziness [and] actually fighting [her] head to try and get it to work'*. Sophie compares her feeling of fatigue to that when both her parents died within two weeks of one another. The feelings of *'loss'*, *'brain fog'*, *'depression'*, *'little interest in anything'* and *'no energy to do anything scare'* her.

For Sophie living with fatigue is a battle; it is like *'swimming through treacle, just everything is a struggle to move, to do anything, to think'*. Sophie has to fight her fatigue, fight her brain to try to *'put it into gear'* and fight her body to make it to work. Everything requires energy; the energy that she doesn't have. Sophie feels as she is not in control of her mind or of her body. She doesn't want to be on this *'autopilot'* when she constantly goes *'through the motions, that [she has] to do stuff, rather than [she] want[s] to do stuff'*. Often her *'head just won't connect'* with the work that she does.

Sophie's fatigue in terms of its severity and pattern changes from one day to another and also *'several times during the day'*. The only predictable element is that it is *'always worst on Monday'* and gets better as the week progresses. Also mornings are difficult, as it takes her a long time to wake up and to get herself going. Her motions are slow, she *'prise[s] [herself] out of bed, roll[s] into the shower'* and doesn't *'really wake up until around 9 o'clock if [she is] lucky'*, but by that time she is already at work in her office. She can't foresee or predict what causes the fatigue and her energy to deteriorate, but she can always judge how tired she is by the amount of coke that she drinks and the amount of work that she is able to do. On a bad day she questions what has she done, but on a good day she can *'fly through loads'*. Sophie paints a picture of how bad her fatigue is with words, mostly metaphors i.e. *'heavy like lead'*, *'absolutely knackered'*, *'brain fog'*; or by talking about various activities requiring a lot of energy and physical strength i.e. *'trying to run uphill'*, pulling herself *'through porridge'*. Sophie identified two types of fatigue: mental and physical. She thinks that *'physical fatigue is affected by the mental'*, but she finds that *'mental fatigue is the worst'*, as it is an ongoing struggle with herself and her brain. This ongoing struggle gets her down and she wishes for somebody to take all her suffering away and to give her a break from it.

Sophie tries to understand what makes her fatigue better, but even when she is on holiday or

rests at home at the weekend it doesn't seem to help. Despite the fact that Sophie's fatigue started prior to her other CD symptoms, she is certain that her fatigue is related to the CD, as she never struggled so much with things before. Sophie finds the '*brain fog*', the '*fuzziness*' and being physically exhausted upsetting and frustrating. She has realised that activity makes her more alert physically and mentally, but she can't keep her activity going for any prolonged period of time as she runs out of energy and can't always find the motivation. Social interaction and a light hearted, relaxed atmosphere also help her to feel less fatigued, but she only has office colleagues for support and company, as she has no energy to go out in the evenings or at the weekend.

Fatigue turned Sophie into an isolated and frustrated person. She sees herself as unreliable, forgetful and lacking energy. Despite being only 37 years old, she feels old before her time, as she needs to rely on her husband's help. She would like to apply for a different position at work, but if the work requires driving, she knows she will not be able to do it, as now (being fatigued) she does not feel safe to drive. Hobby wise, Sophie would like to pursue her interest in photography, but often doesn't have the energy or motivation to do it, so she ends up watching television or playing on the computer.

Sophie hopes that this stage of being fatigued all the time will pass and that she will go back to being her normal self. She asked her consultant and IBD nurses for help, but has been told that fatigue is part of the condition and nothing could be done. This made her even more depressed and frustrated.

6.2.8 Step 8 Develop a composite description of the meanings and essences of the experience representing the group

In this final step of data analysis a *composite description* of the meanings and essences of the whole group experience is constructed (Moustakas 1994). This step combines both textural and structural descriptions of the studied phenomenon from all study participants. Each of the identified themes of the fatigue experience (presented earlier in Table 6-5), incorporated both the textural and structural sub-themes and are presented in the next three chapters. Chapter 7 describes the phenomenon of fatigue (Theme 1), Chapter 8 deals with perceived contributors and ways of managing fatigue (Theme 2 and 3), Chapter 9 presents the impact of fatigue on people's life and describes an overarching experience of living with fatigue (Theme 4 and 5).

6.3 Reflexivity

Reflexivity, as a process of reflecting critically on oneself and one's role in research, was used throughout the data analysis process as a strategy to promote quality and

trustworthiness of the study results. This involved interrogation of my thinking process in shaping my ideas regarding '*what*' the data tell me about the description of fatigue, and '*how*' I was interpreting their meaning. I refrained from referring to literature on fatigue until the final stage of the study, so that the intellectual creativity employed in data analysis came from the data itself.

My reflexivity was aided by the use of a reflective journal and keeping an audit trail - a summary record of events and decisions made in the process of conducting the study (Birks & Mills 2011). The trustworthiness of the results was also enhanced by referring back, on numerous occasions, to the original data to validate the decisions made at every step of the data analysis. Birks and Mills (2011), state that irrespective of the researcher's methodological position, it is imperative for them to be reflexive. Some reflexive techniques, such as memo or journal writing, are criticised in literature as poor measures of quality assurance for expert researchers (Cutcliffe & McKenna 2004). As a novice researcher I found these techniques invaluable in keeping track of the process of actions and feelings related to the decision-making, and to permeate the rationale for choices made and outcomes reached at every stage. Excerpts from my reflective journal (Appendix XVIII) provide examples of the process of data collection and analysis and how my thinking developed over the course of the research process.

6.4 Summary

Moustakas' method for data analysis offers a structured and thorough process, requiring prolonged immersion in, and iterative engagement with, the data. The steps relating to textural description offered an excellent opportunity to identify detailed descriptions of the phenomenon of fatigue. The structural coding and descriptions, on the other hand, provided space and time to look for possible explanations as to the 'cause and effect' relationships between the different factors. Analytical skills and reflexivity were employed throughout the process of the data analysis. The skills of self-awareness were constantly utilised to explore possible biases influencing the analytical process and its results. Discussions with colleagues and supervisors provided reassurance of the results' credibility and the conclusions drawn.

The language used by Moustakas to describe the steps of the analytical process was challenging at times, due to the fact that for many terms such as 'horizontalisation',

‘invariant constituents’, ‘imaginative variations’ and others, although defined by Moustakas, there was little explanation of how this could be done in practice. This was however used in a positive manner and with a certain degree of individual interpretation it allowed for further questioning and exploration of the studied phenomenon. Detailed descriptions of each step, supported by examples of what and how it was undertaken demonstrate how the method was used in practice. The challenges of data analysis in descriptive phenomenology, and a critique and the ways of addressing the challenges are presented in Chapter 10.

Chapter 7 Phenomenon of fatigue in IBD

7.1 Introduction

This first results chapter provides a composite description of fatigue as experienced by individuals diagnosed with IBD. The chapter presents:

- Description of study participants outlining the background and the context for the results presented in this and the following two chapters
- An analysis of language used to describe fatigue
- A composite textural and structural description of IBD-fatigue, its characteristics and dimensions.

The lived experience of fatigue in people with IBD was derived from twenty in-depth unstructured interviews conducted over a period of four months (Sept - Dec 2010) resulting in 23 hours of interview data. The length of interviews ranged from 27 - 87 minutes (mean = 69 minutes). Participants were encouraged to take as long as they needed to tell their story. The difference in the length of the interviews may simply reflect the natural tendency of some participants to share more of their life experiences than others; however, it may also be a result of some participants repeating the same information during their interview.

7.2 Description of participants

Participants were purposively selected according to the inclusion criteria (see Chapter 5). Twenty participants were interviewed; ten men and ten women. At the point of selection, eleven participants were reported to be diagnosed with CD, seven with UC and two (Robert and Julie) reported dual diagnoses of CD and UC. After the interviews, all diagnoses were confirmed by the participants' general practitioners, except the two dual diagnoses; one was confirmed as CD (Robert) and one as UC (Julie), bringing the total number of CD participants to twelve, and the UC participants to eight. Participants' ages ranged from 21 to 82 years (mean 48.6 years). The demographic data specific to each individual participant are presented in Table 7-1.

The length of time since IBD diagnosis ranged from 4 months to 38 years (mean 9.4 years). Eight participants had been diagnosed with IBD for less than 12 months. The length of time experiencing the symptoms of IBD (i.e. the length of time including the pre-diagnosis period, during which symptoms were present) was reported by participants as ranging from 4 months to 39 years (mean 14.9 years). There was, on average, a four and half year lag between the onset of IBD symptoms and the condition being clinically diagnosed.

Each individual's journey from diagnosis to interview was summarised to provide context for their descriptions of fatigue and details of their personal and demographic characteristics that could influence how they experienced and interpreted their fatigue (see Box 7-1 for example). Remaining individual summaries are contained in Appendix XXI.

In reporting the data, verbatim quotes are presented in italics, all participants are referred to by a pseudonym to protect their confidentiality, condition CD/UC= Crohn's disease/ulcerative colitis, and FL= self-reported fatigue level on the day of the interview from 0 - 10 with 0 = no fatigue and 10 = most severely fatigued, for example: [Gary, CD, FL8].

Table 7-1 Demographic and clinical characteristic data of study participants

Name*	Age	Sex	Condition	Years since diagnosis	Years since fatigued	Fatigue level**	IBD activity Index	Relationship status	Geographical location
Sophie	37	F	CD	≤1	3	6	6	Married	West Yorkshire
Andrew	72	M	UC	8	6	6	7	Divorced/Separated	Shropshire
William	62	M	UC	21	21	4	4	Married	Surrey
Mark	47	M	CD	30	6	6	3	Living with partner	Wiltshire
Vicky	24	F	CD	≤1	≤1	8	15	Living with partner	West Midlands
Catherine	49	F	UC	38	38	6	8	Single	Aberdeenshire
Louise	51	F	UC	≤1	2	5	5	Married	London
Robert	82	M	CD	≤1	≤1	4	3	Married	Essex
Fiona	21	F	CD	4	7	7	10	Single	County Durham
Roger	64	M	CD	≤1	≤1	5	14	Married	Somerset
Laura	33	F	UC	≤ 1	≤1	6	5	Living with partner	South Wales
Hugh	39	M	CD	25	25	8	6	Single	Gloucestershire
Henry	46	M	UC	4	1	8	6	Single	London
Sue	58	F	CD	17	19	9	4	Married	Suffolk
Ruby	50	F	CD	6	6	7	9	Married	Norfolk
Alan	54	M	UC	≤1	3	10	5	Living with partner	Cheshire
Harry	45	M	CD	≤1	12	7	9	Married	Greater Manchester
Sally	39	F	CD	≤1	≤1	8	7	Divorced/Separated	Nottinghamshire
Julie	47	F	UC	14	39	9	9	Married	Aberdeenshire
Gary	51	M	CD	11	25	8	7	Living with partner	Derbyshire

Key: Name* - all participants were given pseudonyms; Fatigue level** - participants were asked to score their fatigue on the day of the interview on the scale of 0-10 with 0 = no fatigue and 10 = severe fatigue; M – male, F - female; CD - Crohn's Disease, UC - Ulcerative Colitis; IBD activity index – in CD assessed using Harvey-Bradshaw Index (Harvey & Bradshaw 1980), and in UC assessed using Simple Clinical Colitis Activity Index (Walmsley et al. 1998). Score of ≤4 indicates remission, and score 5≥ indicates active disease in both UC and CD.

Box 7-1 Individual participant description summary – Gary, CD, FL8

Gary, a 51 year old male, was diagnosed with Crohn's disease (CD) 11 years ago. He has been experiencing CD symptoms for 25 years, and also reports being affected by fatigue for the past 25 years. On the day of the interview Gary's fatigue level was 8. He works full time and lives with his partner and 1 child from his previous relationship. It took over 10 years for Gary to be diagnosed with CD. During that time he complained of flu-like symptoms, bouts of diarrhoea and constipation, iritis (inflammation of the front half of the eye), feelings of discomfort in his stomach, aches, pain and tiredness all over. As he found it difficult to deal with the symptoms he also got *'very depressed'*. The flu-like symptoms *'were getting in the way'* of his studying, and he was forced to quit university as he had *'no energy to do anything'*. He said *'nobody put together all these different symptoms, that I might have Crohn's until about 12 years later'*. Also for most of his childhood he was quite a sickly person.

The first treatments suggested to him were acupuncture and herbal medicine as originally he was diagnosed with myalgic encephalomyelitis (ME). In the next couple of months he lost *'a lot of weight'*, which resulted in him *'actually collapsing'*. His GP prescribed him antibiotics, but because he felt worse the following day, he went back to see his GP. The GP sent Gary to the local hospital for further tests. After x-rays he was sent home by the hospital staff, despite his GP's advice to wait for test results. Gary was too *'worn out'* to argue. An hour later his GP phoned and told Gary to go straight back to hospital, as he had a bowel abscess and needed an operation. When he got back to the hospital, he was informed by the consultant that the MRI test had confirmed that *'it's not an abscess; you've got Crohn's so you're all right'*.

Gary was traumatised by his diagnosis. He had heard of Crohn's as he knew somebody years ago who had it. That person most of the time *'was absolutely fine, [but] had really bad episodes of it and had been in hospital for weeks on special diets and medication'*. At the same time he has found it easier since the diagnosis, as until then he thought that he *'was dying and nobody was ever going to find out why'*. He said *'I thought I might have cancer, and I felt guilty for feeling like that, you're being self-indulgent and a hypochondriac, and just felt like I shouldn't be feeling like that, but I did'*.

It took Gary a few months to accept the diagnosis of Crohn's disease before he started getting help. Before his diagnosis, he went *'to counselling for six months, but never opened up to anything, wasn't prepared for it'*. His personal life was affected by his emotional state and his partner left him. Gary's personal *'trauma'* made him *'wake up'* and *'deal with all what was going on'* and he felt he was *'a better person... was much more open about feelings, more honest with [him]self and other people'*. He started to be more responsible about how to manage his health and to cope better with the symptoms.

Gary had always been *'a responsible person'*, and had always gone to work, even though most of the time he felt sick. Even now he feels that it would be so easy not to go to work for *'a couple of days, and then a week, and then two weeks'*. He talked about feeling guilty for wasting medical professionals' time and *'for imagining that, the way he felt was important'*.

Gary sleeps *'really badly'* and often wakes up at night. He also complains about discomfort in his stomach, aches and pains in all his joints, neck, head and shoulders, and all the way down his body.

The individual textural descriptions of fatigue and its experience (as shown in Box 7-1) formed the basis of the composite textural descriptions summarising the experience of IBD-fatigue for the whole group.

7.3 Perceived temporal features of fatigue

Participants reported differing patterns of onset and progression of fatigue, the length of time living with fatigue and an IBD diagnosis varied. For some, the symptom of fatigue first became evident before they were diagnosed with IBD, others observed fatigue at diagnosis, and for others, it slowly crept up as other IBD symptoms worsened or progressed (Table 7-2). Some participants had difficulty recognising when fatigue started in relation to their IBD diagnosis as they were not aware that fatigue can be associated with IBD.

Participants who reported the onset of fatigue before being diagnosed with IBD had, in some cases, considerable delay in their condition being diagnosed. Three participants, Harry, Julie and Gary, were not diagnosed for between 11 - 25 years, despite having 'vague' abdominal symptoms and discomfort. During this time they experienced considerable distress due to not only being physically, but also emotionally unwell, as they perceived fatigue as an indicator of a serious, but undiagnosed disease. Not being believed about how they felt, contributed further to their distress: *'I thought I was dying and nobody knew why'* [Gary, CD, FL8]. The delayed diagnosis of IBD, an unknown and unexplained origin of their fatigue, and lack of support may have contributed to other health and personal problems at the time; Harry lost his job, Gary developed depression and separated from his long term partner, and Julie's marriage broke down and her career was impaired.

Two participants, Fiona and Sophie, also talked about having fatigue before being diagnosed, although their diagnosis was confirmed six to eight months after first having symptoms. Fiona initially put her severe tiredness down to growing, being a teenager and in the last year at school, while Sophie thought that her fatigue was related to grieving following the death of her parents.

William, Louise and Robert, whose fatigue started with the onset and diagnosis of their IBD, directly linked the two aspects, fatigue and IBD, together: *'Almost from the day I developed the Crohn's ... there was a certain amount of fatigue attached, but not always significant'* [Robert, CD, FL4]. The length of time since their IBD diagnosis varied from

under 1 year and 21 years; however they seemed to be coping better psychologically than others, were more positive and motivated finding the way to live with fatigue: *'I think it's a game of learning to be very, very patient, and learning to re-style your whole lifestyle again'* [Louise, UC, FL5]. They also reported lower fatigue levels (4-5 out of possible 10 points) on the day of the interview.

Hugh and Alan, whose fatigue onset was also closely related to the time of IBD diagnoses, reported a higher level of fatigue (8 and 10 respectively). Hugh was diagnosed with IBD 25 years previously, and Alan was diagnosed one year ago, but their fatigue was *'getting progressively worse'* [Alan, UC, FL10], and throughout the interview they both demonstrated a significant level of distress. Distress in IBD was not measured, as at present there is no validated scale to do so.

Another distinctive group of participants, Sally, Andrew, Mark, Vicky and Henry, were those whose fatigue increased over time since their IBD diagnosis. This was the largest group and there was substantial variation in the length of time since IBD diagnosis, from under 1 year to 30 years. The severity of fatigue experienced by participants in this group varied from 6 - 8 on the day of the interview. This group of participants linked fatigue with IBD and, although they were still considerably affected by fatigue (see Chapter 9), they did not report the same level of distress as those whose diagnosis of IBD was delayed and who were unable to explain the origin of their fatigue. Also for some of them, the onset of fatigue was delayed in relation to the onset of IBD. Andrew was diagnosed with UC 8 years ago and has been suffering with *'fatigue for the last 3 years'* [Andrew, UC, FL6]. Mark was diagnosed with CD 30 years ago and fatigue has *'been a real problem for the last 6 or 7 years'* [Mark, CD, FL6]. This delayed presentation of fatigue in relation to IBD diagnosis may be a moderating factor allowing the individual time to accept the UC or CD diagnosis and to adapt to their new, different lifestyle, before they experience another challenge in the form of fatigue.

Table 7-2 Onset and duration of fatigue in relation to IBD diagnosis

Fatigue onset before IBD diagnosis	Fatigue onset at time of IBD diagnosis	Fatigue onset after IBD diagnosis
<i>I can't remember when it was the fatigue started exactly, but it was before my Crohn's [Sophie, CD, FL6]</i>	<i>I was diagnosed with UC 21 years ago, and I've been experiencing fatigue for the same period of time [William, UC, FL4]</i>	<i>I had fatigue for the last 3 years [UC diagnosed 8 years ago] [Andrew, UC, FL6]</i>
<i>I was exhausted. It was like I'd already done a full day's work and I just couldn't carry on. ... I did put it down to being tired. I didn't think that I was ill. So it started before I even was diagnosed [Fiona, CD, FL7]</i>	<i>I've noticed it [fatigue] from about 2 years ago, when I first started having the symptoms [Louise, UC, FL5]</i>	<i>Fatigue has been a real problem for the last 6 or 7 years [diagnosed with CD 30 years ago] [Mark, CD, FL6]</i>
<i>It took 12 years to be diagnosed with CD and I was tired all this time [Harry, CD, FL7]</i>	<i>Almost from the day I developed the Crohn's there was a certain amount of fatigue attached [Robert, CD, FL4]</i>	<i>Over the last 6 - 8 months it's [fatigue] been problematic [diagnosed with CD a year ago] [Vicky, CD, FL8]</i>
<i>I lived with constant tiredness and a certain amount of pain since I was 8 and I wasn't diagnosed until I was 33 [Julie, UC, FL9]</i>	<i>Tiredness and fatigue was always there [diagnosed 25 years ago], but probably the last 6 years have been the worst [Hugh, CD, FL8]</i>	<i>I started noticing fatigue maybe April May this year [6 months ago] and it just seemed to creep up. ... It was only when I started to really fall asleep at work, that I started to become more aware of it [diagnosed with UC 4 years ago] [Henry, UC, FL8]</i>
<i>For 25-27 years I was going through all of the vague symptoms of discomfort in my stomach and the aches and pains and tiredness. I was finally diagnosed with CD 11 years ago [Gary, CD, FL8]</i>	<i>Bleeding and the other symptoms started about 2 years ago, the fatigue was going on, in smaller doses but getting progressively worse [Alan, UC, FL10]</i>	<i>When I was diagnosed with CD I had an operation for an intestinal abscess. For the first 6 months I thought I was always tired because of the healing process, but I'm 18 months post-op [operation] now [Sally, CD, FL8]</i>

Some participants did not know that fatigue commonly arose with IBD: *'I didn't realise that the fatigue was part of the IBD until I read the IBD leaflets and speaking to yourself about the surveys; when I first got IBD I was about 12, 13 and I remember I couldn't get off the settee, I was so, so tired'* [Catherine, UC, FL6]. And Roger said: *'I thought it was my age, I didn't know it's [fatigue] part of Crohn's, it's happened very slowly in many respects. I first noticed it because I always go for a right long walk in the morning, and I couldn't walk more than 500 yards, and when you think 6 months before that I could walk until, well I never got tired really, 15, 20 miles with no problems really. That was when we first noticed it'* [Roger, CD, FL5]. Despite Roger being diagnosed with IBD for less than 1 year and Catherine for 38 years, they both reported a similar fatigue severity (5 and 6 respectively). The difference between these two participants was that Roger had already started regular walks and exercising (and was reporting positive outcomes), and his wife was very supportive and encouraging; while Catherine was *'too tired to even think'* about physical exercise, was frequently in pain due to rheumatoid arthritis, couldn't walk far, was a single parent looking after 12 year old child, was not in a relationship and had no social or emotional support. From this description many different contextual factors seem to play an important role in fatigue onset and perception of its severity.

There seems to be no common pattern to fatigue onset, its severity and duration in relation to the IBD diagnosis. For some participants who reported fatigue before being diagnosed, fatigue was interpreted as an antecedent of impending or ongoing inflammation. For some, disease activity was an antecedent to fatigue, while for others fatigue was not related to the inflammation process: *'It doesn't matter what I have [remission or flare up], I'm constantly tired'* [Sue, CD, FL9].

The order of the cause-effect relationship between fatigue and IBD seems to be different for different participants. Factors such as participants' age and personal circumstances, age at the time of IBD diagnosis, attitudes to fatigue and support systems may all play a role in the severity of fatigue and the trajectory of coping with fatigue. These factors are explored further in Chapters 8 and 9.

7.4 Language describing fatigue

A composite description aims to present the texture and structure of an experience, in this case IBD-fatigue. As previously stated (Chapter 6), *'texture'* or *'textural description'* provides information to a question 'What is it'? And *'structural description'* looks for information to a question 'How does it feel?' or 'What does it mean?' – to provide an explanation for the experience. Following analysis of the data many varying features of fatigue such as different ways of describing fatigue, dimensions, types, pattern and severity of fatigue, were identified and are presented. At times different selection criteria and participants' characteristics, for example CD or UC diagnosis, gender, age or length of time of living with IBD, are considered to explore if these factors affect the way participants describe or experience fatigue. The ways of describing fatigue and its dimensions are presented here; consequences or impact of fatigue are presented in Chapter 9.

7.4.1 Descriptors and dimensions of fatigue

All participants had considerable difficulty in describing their experience of fatigue. When asked to do so, one participant said: *'You just, it's like a, I don't know, it's very strange to put your finger on it'* [Roger, CD, FL5], and another said: *'I haven't really got a perfect word for it'* [Sue, CD, FL9].

Experiences of fatigue varied considerably from one participant to another in terms of its manifestation, severity, pattern and types of fatigue. Participants used a variety of words and different ways of describing fatigue, some talked about **having** fatigue (e.g. fatigue as an entity), while others talked about **being** fatigued (e.g. fatigue as a state of being).

Participants, rather than describing fatigue as entity, were more likely to talk about how fatigue affected their lives. In order to elicit more nuanced descriptions of fatigue the researcher asked the same question (How would you describe fatigue?) at various points in the interview, and some participants were asked to 'paint a picture' of fatigue using words. Ruby, an artist, responded with: *'a big black hole, big black hole I suppose'* [Ruby, CD, FL7], Julie, a writer, said: *'physical heaviness ... just a general lethargy and can't-be-bothered-ness. It's like a kind of physical depression ... feeling under the weather'* [Julie, UC, FL9], and Robert, an English teacher replied: *'I think, the extreme of my suffering, exhaustion if you like, and other times it's just been, just feeling very, very weary, and no inner energy, you lose the - what's the word I need – you lose the aesthetic side of things you know, it is so depressing. ... I'm bone weary is the old way of describing it ... an*

unfamiliar emptiness, a lack of wanting to do things’ [Robert, CD, FL4]. All three participants with either an artistic, creative background or a degree in English struggled to find words to describe fatigue.

These three different descriptions illustrate the varying fatigue experience and they also indicate that there are different types of fatigue, namely physical and mental, presented here as *‘physical depression’*, *‘heaviness’* of the body and *‘weariness’* of the mind. In the description as a *‘big black hole’*, fatigue is portrayed as negative, scary and nonspecific. The consequences of fatigue, presented here as *‘no inner energy’* or *‘lethargy’* and *‘can’t-be-bothered-ness’* indicate that fatigue impacts on motivation *‘a lack of wanting to do things’*, and a wider psychological functioning *‘depressing, unfamiliar emptiness’*. It is interesting that the term ‘fatigue’ is not often used in everyday language: *‘Fatigue wouldn’t have been the first word that I would have used for it, I would have generally said tiredness, but that wouldn’t help’* [Julie, UC, FL9]. The term ‘fatigue’ seems to be imposed by healthcare professionals from medical vocabulary: *‘The doctor in the past has written sick notes saying Crohn’s-related fatigue’* [Hugh, CD, FL8].

A variety of different words such as tired, exhausted, weak, weary, shattered and knackered appeared to be used interchangeably when talking about fatigue. Being fatigued is being *‘absolutely shattered, tired, fatigued and exhausted’* [Andrew, UC, FL6]. Participants cannot and do not try to differentiate between different terms, but by using a few different terms at the same time, they try to communicate the complicated and difficult to explain nature of fatigue: *‘I can’t separate out being tired and being weak, because they both happen at the same time, and I’m knackered so much of the time I can’t tell you. ... I’m shattered, I’m tired out and weak. ... That’s how I would describe it, feeling of being shot at’* [Harry, CD, FL7].

The language used by participants to talk about the phenomenon of fatigue varied greatly. The rich, wide-ranging descriptions of fatigue illustrating its multidimensional features and diversity are summarised in Table 7-3. The descriptors relate to fatigue being presented as a **product**, **process** and **outcome**.

Terminology related to physical heaviness of the body, to lack of strength and energy and difficulty doing things, and to cognitive and mental functioning. All participants had difficulty conveying the feeling of fatigue and to overcome this difficulty, they used many different terms, but this proliferation of terms resulted in disjointed narratives of fatigue, reflecting the elusive nature of the subjective experience. Often the descriptions of fatigue were intertwined and referred to as having fatigue (product) and being fatigued (process), and as physical and mental sensation all present at the same time.

Being fatigued was for some participants not *'having the energy to do anything'* [Louise, UC, FL5], *'a feeling of feeling completely drained'* [Mark, CD, FL6]. When the store of energy is full, battery fully charged, fatigue is at the lowest level; however as the energy reserves are being used, for example for physical and mental activities, then the scale of fatigue goes up. Energy and fatigue are in constant interrelationship, of one going down and the other going up, and vice versa. In a person with fatigue, the use of energy reserves is much faster than in the non-fatigued, disproportionate to the length of time or level of difficulty of the activity, and often they are unable to fully recharge the battery. The sudden loss of energy was compared to: *'pulling the plug out of the sink, the water's just draining away'* [Sue, CD, FL9], or to: *'running on a flat battery all the time'* [Sally, CD, FL8]. This lack of energy and sensation of heaviness and pain, left some participants feeling being unable to do anything and lacking motivation, as they had *'little interest in anything'* [Sophie, CD, FL6]. This lack of energy and motivation further affected an individual's ability, or perception of their ability to do things.

Many phrases describing fatigue related to the participants' cognitive processes and mental functioning such as a lack of clarity of thinking and inability to concentrate. This was compared to *'brain fog'* [Sophie, CD, FL6], or being *'cotton woolly, very like fuzzy'* [Fiona, CD, FL7].

Table 7-3 Ways of describing fatigue

	Fatigue as product	Fatigue as process	Fatigue as outcome
Physical	<i>heavy</i> [Catherine, UC]; <i>really tired</i> [Fiona, CD]; <i>weak</i> [Andrew, UC]; <i>exhausted</i> [Laura, UC]; <i>knackered</i> [Mark, CD]; <i>heavy body</i> [Mark, CD]; <i>extreme tiredness</i> [Vicky, CD]; <i>legs and joints feel like lead</i> [Sophie, CD]; <i>my body feels two tonnes in weight</i> [Vicky, CD]; <i>shot at</i> [Harry, CD]; <i>twice the weight you are</i> [Catherine, UC];	<i>trying to run uphill</i> [Sophie, CD]; <i>swimming through treacle</i> [Sophie, CD]; <i>like having flu</i> [Sue, CD]; <i>like pulling plug out of the sink, the water just draining away and that's how I feel the energy just draining out of my body</i> [Sue, CD]; <i>I could quite easily flake out</i> [Roger, CD]; <i>like running a marathon every day</i> [William, UC]; <i>as though I'm being held back</i> [Roger, CD]; <i>you feel a bit limp</i> [Andrew, UC]; <i>shattered</i> [Andrew, UC];	<i>body completely drained</i> [Mark, CD]; <i>no energy to walk</i> [Henry, UC]; <i>running on a flat battery</i> [Sally, CD]; <i>the smallest thing just zaps every ounce of energy in you</i> [Laura, UC]; <i>body aches</i> [Fiona, CD]; <i>you can't do anything</i> [Laura, UC]; <i>so like out of breath</i> [Mark, CD]; <i>hits you like a sledgehammer</i> [Catherine, UC];
Mental	<i>brain fog</i> [Sophie, CD]; <i>woolly and fuzzy head</i> [Fiona, CD]; <i>brain is a bit addled</i> [Roger, CD]; <i>head's mince</i> [Catherine, UC];	<i>fighting my head to try and get it to work</i> [Sophie, CD]; <i>head feels like it's filling up with mush</i> [Alan, UC]; <i>the cogs of your brain have suddenly gone</i> [Hugh, CD];	<i>grogginess</i> [Alan, UC]; <i>too exhausted to think</i> [Ruby, CD]; <i>cloudy brain, empty brain</i> [Henry, UC]; <i>being woolly in thinking</i> [Sue, CD];
Combined physical and mental	<i>heavy and fluffy and strange</i> [Sue, CD]; <i>big black hole</i> [Ruby, CD]; <i>you are like a vegetable</i> [Roger, CD]; <i>like your body is a shell</i> [Roger, CD]; <i>exhausted and debilitated</i> [Harry, CD]; <i>I have this monster inside me that's laughing</i> [Alan, UC]; <i>like a demon inside me</i> [Alan, UC]; <i>physical depression</i> [Julie, UC]; <i>just a zombie</i> [Hugh, CD];	<i>struggle</i> [Sophie, CD]; <i>debilitating</i> [Harry, CD]; <i>walking through fog</i> [Louise, UC]; <i>bone weary with no inner energy</i> [Robert, CD]; <i>feeling under the weather</i> [Julie, UC]; <i>treadmill of nothingness, in a rut</i> [Catherine, UC]; <i>wanting to sleep all the time, half awake and half asleep, in a dream world</i> [Henry, UC]; <i>trying to flog a dead horse</i> [Alan, UC]; <i>pulling yourself through porridge</i> [Sophie, CD];	<i>it's like aura round you when you don't want to do anything</i> [Roger, CD]; <i>really lethargic, on top of already feeling dozy</i> [Sally, CD]; <i>completely wiped out</i> [Henry, UC]; <i>can't-be-bothered-ness</i> [Julie, UC]; <i>like being on autopilot</i> [Sophie, CD]; <i>seeing things through a fog</i> [Gary, CD]; <i>like you've never slept</i> [Sophie, CD]; <i>very fuzzy about the way that I see the world</i> [Gary, CD]; <i>no staying power</i> [Harry, CD]; <i>feeling drunk, hangover effect</i> [Alan, UC];

To stay awake, participants needed more energy - energy that they did not have: *'My brain was cloudy and my mind would empty and before I would realise, I would be dropping off or fighting to stay awake, so it was just, half awake, half asleep, in a dream world'* [Henry, UC, FL8]. This state of mental 'fog' at times would come on slowly, but at other times it appeared quickly and unexpectedly: *'the cogs of your brain have all suddenly gone'* [Hugh, CD, FL8].

Fatigue was often described by words and sentences that could be interpreted as referring to both physical and mental aspects of the fatigue experience. On one hand fatigue as a product, was presented as all-encompassing state of being: *'heavy and fluffy and strange'* [Sue, CD, FL9] and being just like *'a zombie'* [Hugh, CD, FL8]. On the other hand, fatigue as a process was *'debilitating'* [Harry, CD, FL7], like *'being on autopilot'* [Sophie, CD, FL6] or on a *'treadmill of nothingness'* [Catherine, UC, FL6] without any purpose or sense of control.

There appears to be a connection between mental and physical fatigue, being: *'bone weary with no inner energy'* [Robert, CD, FL4]. This means that both physical and mental dimensions of fatigue are parts of the same entity (e.g. two sides of the same coin). This connection between mental and physical fatigue could co-exist (e.g. both are ingredients or building blocks of fatigue) albeit in different proportions in different participants, or it could be causal (e.g. showing a relationship between the two parts) physical fatigue affecting mental and vice versa: *'I don't think it [mental fatigue] ever happens without the physical fatigue, so it's a negative progression of the fatigue if you like, the physical fatigue comes first, but then if I get to the mental fatigue I know I'm in trouble basically'* [Mark, CD, FL6]. This relationship between mental and physical fatigue is further analysed in the patterns of fatigue section (7.5.3) of this chapter.

Structural analysis of terms describing fatigue in Table 7-3, indicated it can also be categorised in three different ways: 1) what fatigue is - a product described by the use of **nouns**; 2) how it affects people - a process described by the use of **verbs**; and 3) what it feels like - a sensation, an outcome with severity, described by the use of **adjectives**. **Nouns** describe fatigue as a product, a heavy body, with negative consequences on functioning (process): *'My **body** feels **two tonnes of weight**'* [Vicky, CD, FL8] and to move: *'you're having to lift your **legs** to actually help yourself along'* [Mark, CD, FL6]. The reader can almost 'see' the picture in front of their eyes of a person, who has to help themselves to lift their legs, or may need help from others to lift their heavy legs in order to move. This

implies a level of dependency, or disability of the person affected by fatigue. The challenge for the fatigued person and for others around them is that the fatigued person cannot show the ‘fatigue’ as a proof of their suffering, as it is invisible. They can only show the process of functioning (e.g. slow movement), or the outcome of being fatigued (e.g. having to sleep during the day).

Fatigue was presented as a process, with the use of **verbs**: ‘*Energy just **drains down**, **sinks down**, leaving me with just heavy, heavy feeling, as I could easily **flake out** ... just like being hit with a sledgehammer*’ [Catherine , UC, FL6]. Examples reflecting different types and categories of fatigue are presented in Table 7-4. **Adjectives** such as: **heavy**, **overwhelming**, **knackered**, **shattered**, **dead**, all referred to the sensation of fatigue and are further discussed later on in this chapter (Section 7.5.1) under physical and emotional sensations.

Table 7-4 Descriptors of dimensions of fatigue (examples)

Physical fatigue			Mental fatigue		
Product	Process	Outcome	Product	Process	Outcome
<i>Heavy body</i>	<i>Like water draining away</i>	<i>Drained out of energy</i>	<i>Brain fog</i>	<i>Being woolly in thinking</i>	<i>Too exhausted to think</i>
<i>Overwhelming heaviness</i>	<i>Swimming through treacle</i>	<i>Running on a flat battery</i>	<i>Woolly head</i>	<i>Fighting your head to try and get it to work</i>	<i>Woolly in thinking</i>
<i>Aching body</i>	<i>Like having flu</i>	<i>Like out of breath</i>	<i>Minced head</i>	<i>Difficult to remember</i>	<i>Wiped out</i>
<i>Legs and joints feel like lead</i>	<i>Like running a marathon every day</i>	<i>Cannot do anything</i>	<i>Empty brain</i>	<i>Like head is filling up with mush</i>	<i>Feeling drunk</i>

Some participants referred to fatigue as a product and as a process, both being present at the same time: ‘*When it [fatigue] was at its worst ...my whole body felt exhausted that even the smallest thing just zaps every ounce of my energy ... I feel unfit, like I can’t do anything*’ [Laura, UC, FL6]. This may indicate that the presence of fatigue (**product**), demonstrated here by ‘*exhausted body*’ may initiate the fast process of losing a large amount of energy e.g. ‘*zaps every ounce of energy*’ (**process**), has an immediate effect on people’s ability to

function e.g. '*can't do anything*' (**outcome**), with the consequences disproportionate to a particular activity that individuals were involved in at the time. The consequences of fatigue are analysed in Chapter 9.

All the terms used to describe fatigue have negative connotations for the individual affected by it. Fatigue was portrayed as complicated and complex, and as '*the extreme of suffering and exhaustion*' [Robert, CD, FL 4]. Participants found it difficult to describe and explain its complexity. Often they used metaphors and similes to try and 'paint a picture' of their fatigue experience, but not all participants were successful in communicating a clear message or image of fatigue. Examples taken from everyday life may be more useful in describing fatigue, rather than invented, imaginary, therefore unreal concepts. Perhaps it may be easier for the reader to imagine fatigue as a '*heavy body*' [Mark, CD, FL6], '*water draining away*' [Sue, CD, FL9], '*running a marathon every day*' [William, UC, FL4], being '*hit with a sledgehammer*' [Catherine, UC, FL6] or '*seeing things through a fog*' [Gary, CD, FL8]; rather than '*being a zombie*' [Hugh, CD, FL8] or feeling as you have '*a demon inside ... have [a] monster inside that's laughing*' [Alan, UC, FL10]. This invisible and intangible nature of fatigue may play a crucial role in participants not always feeling being believed about the symptom of fatigue.

The use of a wide variety of terms by participants to describe fatigue helps to create a much better understanding of the phenomenon of fatigue. At the same time it demonstrates the complex, dynamic and varied nature of the experience. Counting the frequency of words used to describe fatigue was not part of this study; however, some words e.g. '*tired*', '*exhausted*', '*heavy*', '*running a marathon*', '*walking through fog*', '*woolly thinking*' appeared to be frequently used by different people. This may demonstrate there are many commonalities in the experience of fatigue. Some other phrases e.g. '*zombie*', '*pulling yourself through porridge*', '*bone weary*', may indicate that fatigue is experienced differently by different people, or it may indicate it is a phenomenon that participants found it difficult to clearly explain.

Use of abstract terms such as '*being a zombie*' or '*have a demon [or] a monster inside*' could be seen as a way of the participants trying to communicate the unfamiliarity of the symptom of fatigue. The definition of 'zombie' is stated as 'an offensive term for a person considered lacking energy, enthusiasm, or ability to think independently' (The Oxford English Dictionary, 2012). Whereas synonyms for 'demon' mean mischievous, evil spirit, and for 'monster' mean huge, giant, enormous or monstrous. All these terms imply that

fatigue is seen to be a malevolent spirit of a scale beyond the participants' ability to deal with, and beyond their control, with negative value judgements directed at the person affected by it.

7.4.2 Metaphors and similes

Structural analysis of the data reveals that metaphors and similes are frequently used by participants when talking about their experience of fatigue. The metaphors and similes could be categorised into those describing fatigue as a product, process and an outcome; relating to either physical or mental aspects of fatigue, or encompassing physical and mental aspects of fatigue both at the same time (Table 7-5). Metaphors and similes used to describe physical dimensions of fatigue predominantly relate to body heaviness, pain, weakness and lack of energy: *'My whole body feels completely drained of energy'* [Mark, CD, FL6]. Fatigue was being compared to the feeling of being unfit physically, which lead to participants not being able to do things.

Table 7-5 Metaphors and similes used to describe dimensions of fatigue (examples)

Physical			Mental			Physical and mental together		
Product	Process	Outcome	Product	Process	Outcome	Product	Process	Outcome
<i>Body feels two tonnes heavy</i>	<i>Like trying to run uphill</i>	<i>Body completely drained</i>	<i>Brain fog</i>	<i>Fighting my head</i>	<i>Grogginess</i>	<i>Body is a shell</i>	<i>Like you have never slept</i>	<i>Like an aura round you</i>
<i>Flat battery</i>	<i>Like running a marathon every day</i>	<i>Like out of breath, could flake out</i>	<i>Woolly head</i>	<i>Head is filling up with mush</i>	<i>Cloudy brain</i>	<i>Big black hole</i>	<i>Pulling through porridge</i>	<i>Like being on autopilot</i>
<i>Body feels like lead</i>	<i>Like pulling plug out</i>	<i>Hitting a brick wall</i>	<i>Mince head</i>	<i>Cogs of brain have gone</i>	<i>Being woolly in thinking</i>	<i>Like a vegetable</i>	<i>Flog a dead horse</i>	<i>Like you have never slept</i>

When described as a process, physical fatigue was compared to a prolonged event (running a marathon), with considerable level of difficulty (run uphill), or sudden loss of energy resulting in painful and unpleasant experience (hitting a brick wall). This made participants feel weak and lacking energy, as if going to *'flake out'* [Andrew, UC, FL6].

Metaphors used to describe mental dimensions of fatigue, on the other hand, relate to having limited or no capacity to think (**product**), or having to fight the head (**process**) to be engaged in cognitive activities (**outcome**). Participants imply having limited or no control of their cognitive processes. Fatigue is like being in a dreamland, being out of control, and **having** to do things rather than **wanting** to do them.

Participants often provided descriptions related to both mental and physical aspects of fatigue simultaneously, such as feeling sleep deprived for a prolonged time, which in turn left them feeling unable to do anything or not wanting to do anything. Those who compared their feeling of fatigue to that of being sleep deprived, talked about feeling as they are an autopilot or in a dreamland: *'Just wanting to go to sleep right there and then forget about it all. ... That's all I would care about, everything else really wasn't important'* [Henry, UC, FL8].

The metaphors reflecting fatigue as a feeling of being like a 'zombie', 'a vegetable' or like 'pulling through porridge' or like 'you have never slept', all indicate participants' inability to function 'normally' (as before fatigue), and lack of control over their body and mind. This is further analysed in Chapter 9, impact of fatigue on functioning.

Comparison between different words and metaphors used to describe fatigue by different sub-groups (e.g. CD and UC participants, different age and gender, participants newly diagnosed with IBD and those who were diagnosed for a longer period of time) demonstrated that they used the same or similar terms (Appendix XXII), and all groups struggled equally to describe their experience. This seems to indicate there is no evident difference between fatigue experiences depending on these factors. For all the study participants, words seemed not to fully capture their experience, as they lacked a suitable vocabulary to adequately describe their fatigue.

7.4.3 Fatigue versus tiredness

Participants were convinced that fatigue is part of their IBD, and they were keen to stress the difference between fatigue related to IBD and 'normal' tiredness related to daily life: *'Fatigue is, I don't know if that's the right word actually. ... Fatigue is a funny word isn't it. Fatigue is when we've been labouring all day and you're fatigued, funny word. ... But you don't, you're tired after hard work'* [Roger, CD, FL5].

The explanation of differences between the meaning of ‘fatigue’ and ‘tiredness’ were not always clear: *‘It [fatigue] is part of the colitis, [but] it’s a strange fatigue, it’s not like ordinary tiredness’* [Alan, UC, FL10].

The attempt to explain the differences between the terms ‘fatigue’ and ‘tiredness’ would indicate that ‘tiredness’ is a result of intended, demanding, predominantly physical activity, an activity that participants can clearly link with the feeling of being tired, and at the same time often produces a positive anticipated outcome. The term ‘fatigue’, on the other hand, would indicate the state of feeling that is undesirable, unintended and its origin often cannot be explained.

One participant tried to explain the difference between fatigue and tiredness in a more visual way: *‘This fatigue is different to tiredness, very, very different. ... The fatigue is just totally, totally different. It’s almost, you know if you have a pair of scales, and you had tiredness and fatigue, fatigue would be the one down here with the heaviest weight, the tiredness would be at the top being the lightest. ... That is, physically, the only way I can describe it’* [Sally, CD, FL8]. It would seem that Sally’s explanation of the difference between fatigue and tiredness relates to its severity.

Participants even questioned if ‘fatigue’ is the best word to use to reflect the feelings that they experience. For some the term is an alien, unfamiliar word that is not used in everyday vocabulary, a word that does not truly fit with or reflect their experience, and creates considerable problems in describing the feeling of fatigue to others. For others ‘fatigue’ seems to be used interchangeably with the term ‘tiredness’ and often it is difficult for them to identify distinct differences between the two. If ‘tiredness’ is seen as an effect of everyday normal functioning (within the control of the individual), but then the same term is used to describe the symptom of ‘fatigue’ (pathological symptom) for which people have little or no control, it may lead to ‘normalisation’ of fatigue. This may result in fatigue being seen as ‘a normal’ aspect of life, requiring no medical intervention. Due to the challenge that participants have in describing fatigue to others, and because of the many varying and sometimes contradictory terms used, some participants suffer fatigue in silence, or they give up trying to explain it to others (e.g. friends, relatives or healthcare practitioners). Management of fatigue is presented in Chapter 8.

7.5 Perceived characteristics and dimensions of fatigue

From participants' descriptions of experiences three different dimensions of fatigue were identified, namely fatigue sensations, severity, and patterns.

7.5.1 Physical and psychological sensation of fatigue

Fatigue was described as physical and psychological sensations. Physical body sensations of fatigue presented as pain, heat, heaviness and breathlessness. These feelings were reported, at times, to affect the whole body (**core fatigue**): *'from head to toe my body's completely drained'* [Sally, CD, FL8], and at times were localised more in the distal parts of the body e.g. limbs, shoulders and head (**peripheral fatigue**): *'I get heat behind my eyes, it stings to keep them open, tension in my jaw, my eyes are dropping, my eyes are stinging'* [Vicky, CD, FL8].

The sensation of heaviness often turned into a feeling of pain; pain that was a whole body sensation or was localised in specific areas: *'I'm not medical or anything like that, I just know – it almost hurts, I don't know if that explains anything, but it almost hurts, the whole body just seems to go. ... It's just all over your body, you feel as if, if you moved, something would crack. ... That's about the nearest I can get to describing it, it's most uncomfortable'* [Andrew, UC, FL6].

Three participants discussed fatigue-related breathing problems, Sophie would *'struggle to breathe'* [Sophie, CD, FL6], Laura *'gets so, like out of breath'* [Laura, UC, FL6], and Mark *'[gets] breathless very quickly'* [Mark, CD, FL6]. It was unclear whether the 'breathlessness' was the result of the feeling of 'heaviness', or a symptom of fatigue.

Some participants described fatigue as a psychological sensation, similar to sadness or depression. Sophie compared her feeling of fatigue to that of when her parents died: *'When I had bereavement counselling a while ago, the brain fog I have some days is like it was after my Mum and Dad died'* [Sophie, CD, FL6]. It was, however, difficult to determine if sadness and depression were sensations of fatigue or rather a response to fatigue: *'Malaise ... [and] a feeling that like my body's a shell, there is nothing in there, makes me go into periods of silence ... [and] make me feel bloody hopeless'* [Roger, CD, FL5]. Fatigue and feelings of sadness and depression were frequently linked. Most participants talked about having low mood or depressive feelings as a result of being fatigued, or as a factor

contributing to fatigue. The relationship between these two factors is considered further in Chapters 8 and 9.

7.5.2 Severity of fatigue

In attempting to describe the severity of fatigue, participants used descriptive language such as adjectives, similes and word repetition. They talked about being '*completely exhausted*' [Laura, UC, FL6], '*completely wiped out*' [Henry, UC, FL8], '*extremely tired*' [Vicky, CD, FL8], '*really, really tired*' [Fiona, CD, FL7], '*very, very weary*' [Robert, CD, FL4], or '*heavy like lead*' [Sophie, CD, FL6].

A few of the participants used a numeric scale to reflect the severity of fatigue: '*There are different stages of the fatigue; sometimes it's very heavy, sometimes it's not quite so heavy. I mean on a score of 1 to 10, when it's really bad it's sort of 8 or 9, or even 10 when it's very, very bad, and then it can go down to about 6 or 7*' [Sue, CD, FL9]. During the recruitment to the study a numeric scale on 1-10 was used to assess participants' fatigue and its' severity. It is possible that participants were influenced by the prior experience of quantifying their fatigue severity in a numeric format.

The severity of fatigue was judged by participants' ability to be physically active and the extent to which their activities were affected: '*If I go out for a walk, my legs can be so heavy that I use that now, almost as a guess, how quickly do I do my walk, and how much effort that seemed to be tells me what level of tiredness I'm at for the day*' [Julie, UC, FL9]. The severity of fatigue was also judged by participants on the basis of other aspects of their life (e.g. social, emotional functioning) being affected, addressed in Chapter 9.

7.5.3 Pattern of fatigue

The patterns and characteristics of fatigue reported by participants were categorised into three groups: constant fatigue, unpredictable peaks of fatigue, and predictable daily and/or weekly pattern of fatigue (Table 7-6).

Table 7-6 Patterns of fatigue and their characteristics

Constant fatigue	Unpredictable peaks of fatigue	Predictable daily and/or weekly pattern
Present all the time, every day	Sudden and unpredictable	Changes few /several times during the day
Consistent low level energy	Cannot be controlled	Daily patterns vary: mornings are the worst and improves as day progresses; or mornings are the best and it deteriorates as the day goes on
Doesn't fluctuate a lot	Fast, worsening severity	Weekly pattern: some good days and some bad days
May get progressively worse	Unpredictable severity and duration of the peaks	Mondays are worst and it slowly gets better as the week goes on; or fatigue gets worse towards the end of the week

7.5.3.1 Constant fatigue

Some participants reported a constant, low level of fatigue: *'I am constantly tired all day every day'* [Sally, CD, FL8], with no or very little fluctuation: *'The tiredness doesn't actually get any worse, but it doesn't get any better either'* [Sue, CD, FL9].

For others, fatigue was getting progressively worse over time: *'I'm really tired all the time, [but] the last 6 years have been the worst ... and probably the last 2 to 3 have been you know, very difficult'* [Hugh, CD, FL8]. Many participants have been suffering with fatigue for a long time, they did not remember how it feels to feel *'normal'*, not fatigued: *'I can't remember the last time I woke up and felt well, I really can't, it's been a long time'* [Ruby, CD, FL7].

7.5.3.2 Unpredictable fatigue

Some other participants talked about sudden and unpredictable peaks of fatigue: *'It [fatigue] may hit me on like, just like a sledgehammer'* [Catherine, UC FL6]. Others explained that fatigue developed more slowly: *'Some days it [fatigue] creeps in gradually and I'm aware it's coming on ... and other times it can happen far more rapidly, so it hits me like the side end of a truck'* [Alan, UC, FL10]. This unpredictability of fatigue meant that the participants had no control over the symptom: *'If you were to ask what [fatigue] would be tomorrow, who can say ... it's just impossible to know'* [Julie, UC, FL9]. The

unpredictability of fatigue related to its worsening severity as well as its duration: *'I can appear that I'm functioning quite well, but then the fatigue will just hit me almost sort of instantly, that day and that will be it then for the rest of that day or for that week'* [Laura, UC, FL6].

7.5.3.3 Predictable daily pattern of fatigue

For many participants fatigue severity changed in a predictable pattern during the day and from one day to another. These fluctuations were different on different days and varied between participants (Figure 7-1).

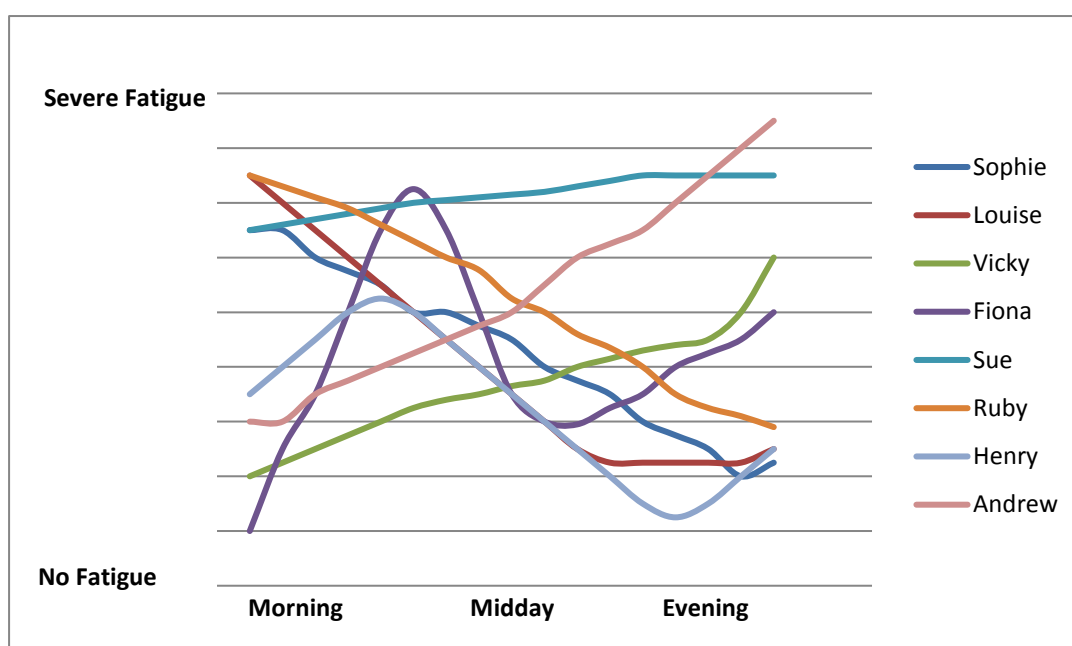


Figure 7-1 Presentation of diurnal patterns of fatigue - examples

Many participants (Mark, Vicky, Robert, Fiona, Roger, Laura, Hugh, Julie) reported feeling less fatigued in the morning, and then as the day progressed, their fatigue would change, although the extent and frequency of the change differed between people. For Vicky, Roger, Hugh and Julie daily fatigue would change in an increasing, linear way. They would frequently start with more energy (less fatigue) in the morning and would get more fatigued as the day progressed: *'It's not too bad in the morning. ... Mine [fatigue] tends to come from about sort of 3 o'clock onwards and by the time I get home from work, that's about me done for the day'* [Vicky, CD, FL8]. Vicky works full time and she queries if her daily

pattern of fatigue is related to her daily structure at work; however, Julie's fatigue has a similar pattern *'Mornings are fine, afternoons good or bad, evenings discount them'* [Julie, UC, FL9] and she is self-employed, working from home with less a rigid structure to her day.

For participants who do not work, all the *'days are very similar to one another'* [Andrew, UC, FL6]. Andrew, who is retired, does not change his routine and his days are structured around toilet trips and meal times. Nevertheless, his energy levels depleted as the day progressed to the point of absolute exhaustion: *'I just get tireder and tireder and my eyes start closing and I'm ready for sleep. ... It is exhaustion you know, I can't even sort of stand up, I'm just lying over the side of the chair and just – nothing, absolute nothing, just so absolutely shattered, tired, fatigued whatever you might like to call it'* [Andrew, UC, FL6]. Andrew explained that mornings and evenings were the worst, because *'usually'* his bowels are most active in the morning and he has run out of energy by the evening: *'Sometimes in the evenings, it's absolutely awful because the whole body just seems to, just to have nothing about, and I can't even sit like this [straight up], I've just got, I just don't know what to do with myself, and I have to hang over the side of the arms and things like that. It really is distressing, because I just don't know what to do with myself, I'm that tired. ... It's not very pleasant while it's happening, because I can't even stand up'* [Andrew, UC, FL6].

There were some participants (Fiona, Henry), whose fatigue level changed a few times during the day, with one or two peaks of severe fatigue: *'I seem to be alright in the morning, and then about tea time I'm alright then, but it's like that middle bit, late morning to early evening, I'm shattered'* [Fiona, CD, FL7]. Others (Sophie and Louise) felt more fatigued first thing in the morning and got better as the day progressed: *'Morning is a very bad time ... and then the afternoon's not too bad, and then the evenings again I'm a bit tired'* [Louise, UC, FL5].

Alan believes his daily fatigue pattern relates to food consumption: *'This is a pattern with me with the fatigue where I narrowed it down to, where I'm all right if I don't have anything to eat. So if I go 8 to 10 hours and avoid food, as ironic as it sounds, my energy levels seem pretty constant. But I can't obviously do that, because I'm diabetic. ... Once I have something to eat, usually, it takes, sometimes it's 20 minutes, today it's a bit longer, it's been an hour before you can feel the fatigue creeping in'* [Alan, UC, FL10].

Daily pattern of fatigue may be linked to participants' daily pattern of activities, sleep

quality and duration, or food digestion; however it cannot be fully explained by these influences alone and other factors need to be considered as possible contributors to fatigue. The full range of possible factors related to fatigue and their impact on the pattern of fatigue are analysed in Chapter 8.

7.5.3.4 Predictable weekly pattern of fatigue

In terms of weekly fatigue patterns (Figure 7-2), some participants (Vicky, Laura and Hugh) felt less fatigued at the beginning of the week and more fatigued towards the end of it: *'I find the beginning of the week is slightly better, so Monday, Tuesday I'm not too bad, and as the week goes, generally by Thursday I'm feeling quite exhausted'* [Laura, UC, FL6]. For others it was the opposite: *'Mondays are the worst: I really, really struggle to get going on a Monday, [and] it [fatigue] slowly gets better as the week goes on'* [Sophie, CD, FL6]. Sophie is not sure if the pattern is linked to the fact that she has *'a lie-in on Sunday'* and her routine changes or to the fact that she does many *'house chores at the weekend'*.

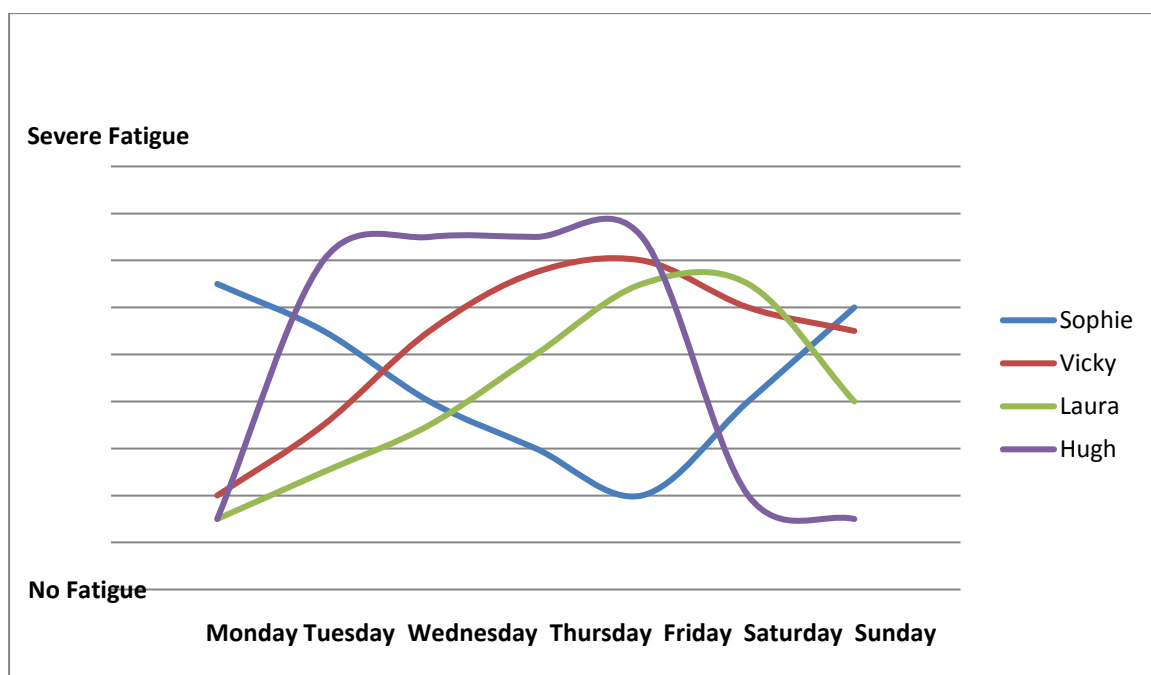


Figure 7-2 Presentation of fatigue patterns during the week – examples

Participants presented fatigue patterns as either constant and relatively stable, or unpredictable and constantly changing; but in all instances fatigue was seen as unpleasant, distressing and debilitating. While some participants were able to describe a clear fatigue

pattern and at times offered an explanation or a possible reason for it, many were less consciously aware of their daily and weekly fatigue pattern, what was causing it and how this could be moderated or managed.

7.6 Perceived types of fatigue

Many participants talked about physical and mental fatigue as the main types affecting them: *'I know fatigue can be a physical thing or it can be a mental. ... Generally for me at the moment, the fatigue is more of a physical thing with just general exhaustion'* [Laura, UC, FL6]. Physical fatigue was portrayed as *'lacking in energy'* and *'incapacity to do stuff'* [Mark, M4, CD, FL6]. Some participants also found it easier to talk about physical fatigue: *'Well, obviously the easier side to talk about is the physical side where I would get tired as the day goes on and you would have the physical symptoms'* [Hugh, CD, FL8]. The physical and cognitive symptoms of fatigue are summarised in Table 7-7.

Some participants talked about the general feeling of exhaustion, when fatigue was *'really bad'*; when fatigue was less severe they were able to identify pain and discomfort in localised areas of their body: *'I get tiredness but I get quite a lot of joint pain and knees and my legs in particular. ... Probably my head quite a bit, because I feel tired, my eyes will feel heavy, when it's really bad my arms and legs would just feel like a ten ton weight, every movement would just feel so heavy'* [Laura, UC, FL6]. The physical sensation of pain, and muscular tension were accompanied by frequent signs of sleepiness: *'In the afternoon I would be forever yawning. ... I would get quite achy, particularly either it would be headachy or kind of a muscular kind of, a tension kind of feeling'* [Hugh, CD, FL8]. Some compared their fatigue to *'minor flu symptoms ... [that] just takes over my whole body ... [and] sometimes I don't even feel the other symptoms because the tiredness numbs everything else'* [Sue, CD, FL9].

Table 7-7 Symptoms of fatigue for each participant

Physical symptoms								Cognitive symptoms					
Name	1	2	3	4	5	6	7	Total	8	9	10	11	Total
Sophie	•	•		•				3	•	•		•	3
Andrew	•							1					0
William	•	•					•	3					0
Mark	•	•			•		•	4	•		•		2
Vicky	•	•	•			•		4		•	•	•	3
Catherine	•							1		•	•	•	3
Louise	•	•					•	3		•	•		2
Robert	•	•						2			•		1
Fiona	•	•	•					3	•	•	•	•	4
Roger	•							1	•		•	•	3
Laura	•	•	•	•		•		5	•	•	•	•	4
Hugh	•	•		•				3			•	•	2
Henry	•			•				2	•	•		•	3
Sue	•	•	•	•	•	•	•	7	•	•	•	•	4
Ruby	•	•		•		•		4	•		•	•	3
Alan	•	•		•	•		•	5	•	•			2
Harry	•							1	•		•		2
Sally	•	•	•					3	•		•	•	3
Julie	•							1		•	•		2
Gary	•	•						2	•	•	•	•	4

Key: (•) – presence of symptom; 1 – Sensation including whole body (e.g. pain/ numbness/ shortness of breath); 2 – Localised sensation (e.g. heaviness, pain and tension in arms/ shoulders/ legs/headache); 3 – Stinging eyes/ heat behind eyes; 4 – Yawning /sleepiness; 5 – Unsteady on feet/ dizzy/hangover effect; 6 – Slumped posture; 7 – Flu like symptoms; 8 – Confused or disoriented; 9 – Difficult to think (e.g. fuzzy/cotton woolly/mush in head); 10 – Difficult to concentrate; 11 – Memory problem (e.g. not taking new information in or recall problem)

Cognitive symptoms of fatigue reported by the participants referred to disorientation and confusion, fuzziness in thinking, difficulty concentrating and memory problems (Table 7-7). The sensation of *'brain fog'*, or *'walking through fog'*, *'cotton woolly head'* and *'mush in head'* (see Table 7-3), all created the feeling of disorientation and confusion: *'It's like a halo round your head'* [Roger, CD, FL5]. Mark was the only one who talked about mental confusion accompanied by the feelings of dizziness: *'I get a feeling of mental confusion at times ... and suddenly [everything] will just go spinning, spinning around, and I feel as if I'm going to faint'* [Mark, CD, FL6].

Mental fatigue appears to be a progression from physical fatigue and it was seen as a worse, more severe type of fatigue than physical: *'My concentration can be quite poor; when my physical fatigue was quite bad I also noticed that not just my concentration, but sometimes*

my memory was affected' [Laura, UC,FL6]. Mark tried to explain his experience of physical and cognitive fatigue: *'It's not too bad if I'm able to read a book or do something like that, but if I get to the stage where I'm unable to even do that, then that is mega frustrating and I suppose that's what I mean by the difference between physically fatigued and mentally fatigued'* [Mark, CD, FL6]. Mental fatigue was perceived as worse, because for participants it meant that the fatigue had progressed to a next, more severe level. This supports the notion of a temporal relationship between physical and cognitive fatigue, with physical leading to cognitive: *'The heavy tiredness is the worst one, the tiredness where it just makes you feel sleepy, it makes your eyes feel heavy, it makes you disorientated even sometimes'* [Sue, CD, FL9].

The temporal order of physical fatigue leading to cognitive fatigue was, however, not confirmed by all participants, as for some it was in the reverse order: *'My brain is saying, no I don't want to move, I'm happy here, no don't want to move - too much energy. That's the ongoing struggle, and so that's another reason why it's mental rather than the physical because I'm struggling with all the stuff inside my head'* [Sophie, CD, FL6]. Sophie thought her physical fatigue was influenced by mental fatigue, but finds mental fatigue worse as it affects her motivation.

For some people, recovery from mental fatigue appears to be more rapid and improves quicker than physical fatigue: *'My mental fatigue has been quite bad on occasions as well, but I suppose that seems to have got better quicker than my physical fatigue'* [Laura, UC, FL6]. The relationship between physical and cognitive symptoms of fatigue were analysed (Table 7-8). One individual (Sue) who reported the highest number of physical symptoms of fatigue (n=7) and highest number of cognitive symptoms (n=5), also reported a high level of fatigue. However, this pattern, namely a high number of physical and cognitive symptoms of fatigue equals greater fatigue, was not observed in other participants. This is a strong indication that other factors, possibly type of fatigue and/or individual responses to the situation, rather than just number of fatigue symptoms, plays a role in its perceived severity.

Table 7-8 Physical and cognitive symptoms of fatigue and reported fatigue level

Participant	Number of physical symptoms	Number of cognitive symptoms	Fatigue level*
Sue	7	4	9
Alan	5	2	10
Laura	5	4	6
Mark	4	2	6
Vicky	4	3	8
Ruby	4	3	7
Sophie	3	3	6
William	3	0	4
Louise	3	2	5
Fiona	3	4	7
Hugh	3	2	8
Sally	3	3	8
Robert	2	1	4
Henry	2	3	8
Gary	2	4	8
Andrew	1	0	6
Catherine	1	3	6
Roger	1	3	5
Harry	1	2	7
Julie	1	2	9

Key: * Self-reported fatigue on 0 – 10 scale on the day of interview

As indicated earlier, longevity was referred to by some participants as a way of classifying fatigue. Many participants talked about chronic fatigue as an *'ongoing struggle'* [Sophie, CD, FL6] and becoming more *'incapacitated and less able to do stuff'* [William, UC, FL4]. Some participants referred to fatigue as *'good fatigue'* or *'bad fatigue'*. If their level of fatigue was attributed to and could be explained by their level of planned and intended physical activities (e.g. exercise), then they would refer to it as good fatigue, which was expected and almost desirable: *'Sometimes it's like I can feel exhausted and feel good about it because I might have done quite a bit'* [Gary, CD, FL8] and another said: *'If I could exercise then I'd probably feel a better sort of tired, whereas the fatigue isn't a good sort of tired, it's a urgh sort of tired for want of a better word, I can't really explain it, it's a bad sort of tired'* [Vicky, CD, FL8]. Participants referred to 'bad fatigue' when they could not explain the reason for it and it affected their level of functioning and control.

7.7 Summary

This chapter captured the essence of fatigue and provided it with thick description. The invisible, but complex and complicated nature of fatigue experience has been encapsulated in many different formats: as a product (having fatigue), a process (being fatigued) and a symptom (feeling fatigued). All three components constitute the description of the phenomenon of fatigue and its experience.

The wide variety of terminology used to explain and describe fatigue demonstrates and supports its complex, multifaceted and multidimensional nature. To transform the written descriptions of fatigue, taxonomy has been provided in a visual form (Figure 7-3).

The varied language and the use of metaphors and similes, on one hand help capture the diversity and severity, but on the other hand demonstrate the challenge that individuals affected by fatigue face when trying to describe the symptom to others. There is no ideal term, or a group of terms, that best encapsulate the entire experience of fatigue, and there is no simple way of describing it. This means that individuals reporting fatigue, in whatever terms they use, should be believed and listened to and their complaints should be taken seriously. Some participants were not informed or not adequately informed by healthcare professionals that fatigue is one of the symptoms of IBD. The lack of awareness of fatigue may have stopped some people from reporting fatigue and from seeking support and advice for the complaint.

Some temporal features and characteristics (pattern, severity, types and sensation) of fatigue were identifiable for some of the individuals. However, due to variability in fatigue severity, duration and a feeling of not being able to fully explain and control it, participants reported predominantly negative aspects of their fatigue experience. Fatigue and its multiple forms and patterns often have far reaching consequences in the physical, psychological, cognitive and social aspects of life, for the individual affected by it, and these are described in Chapter 8.

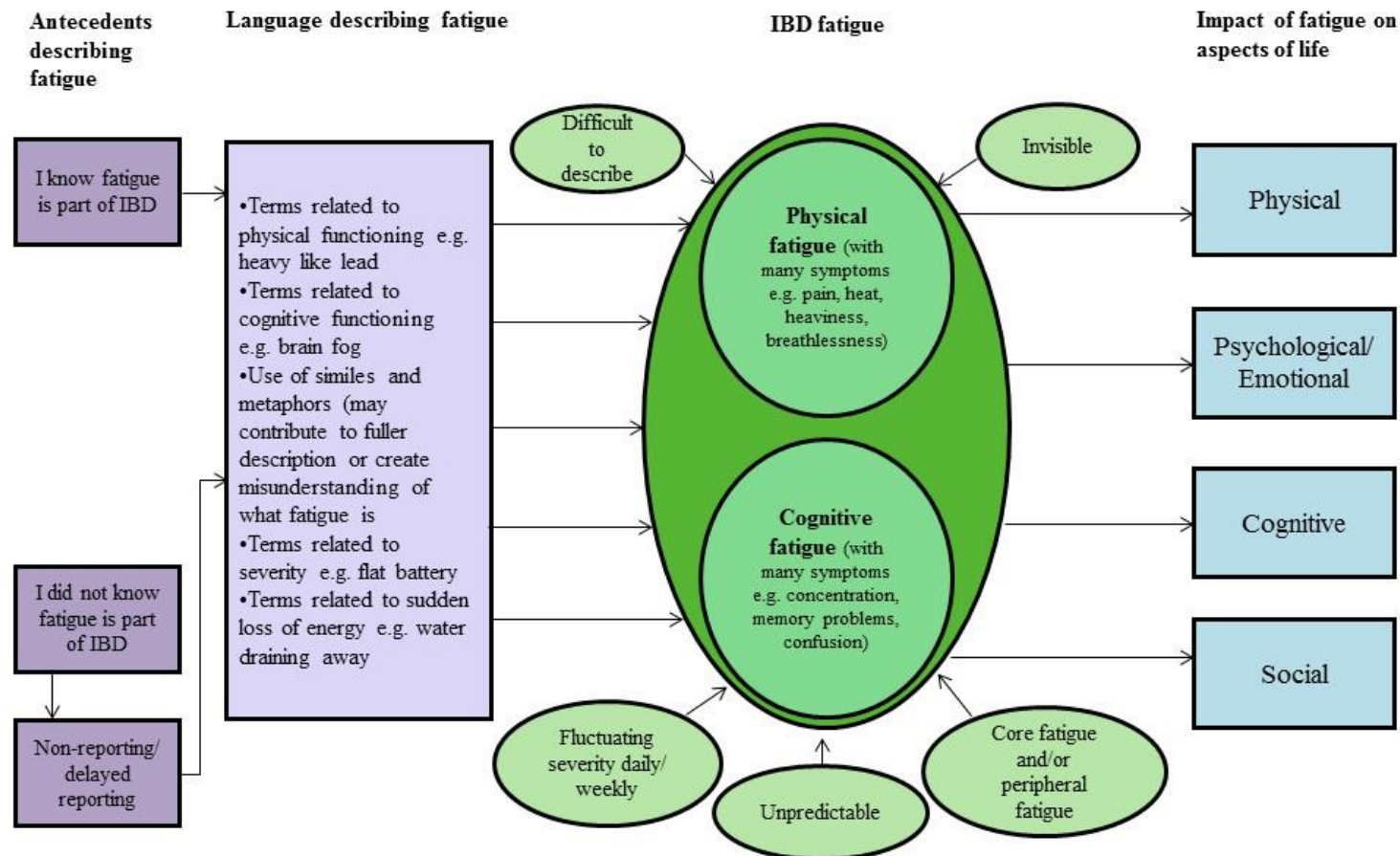


Figure 7-3 IBD-fatigue taxonomy

Chapter 8 Perceived contributors to and methods of managing IBD-fatigue

8.1 Introduction

In the previous chapter a description of fatigue and its features were presented. This chapter aims to analyse:

- The contributors to fatigue as perceived by participants, and
- The different methods of managing fatigue.

Participants identified many different perceived contributors to fatigue and these are summarised into four categories in the first part of the chapter: physical, psychological, cognitive and situational (Table 8-1). The second half of the chapter deals with the methods used by the participants to manage fatigue, arranged under the same four categories.

Table 8-1 Factors perceived as contributing to fatigue

Physical	Psychological	Cognitive	Situational
Factors related to IBD	Stress	Mental activity and concentration	Environmental factors
Factors related to the individual	Anxiety and depression		Lack of support and understanding
Factors related to other health problems	Negative frame of mind and negative feelings		

8.2 Physical contributors to fatigue

The many physical factors perceived by participants as contributing to fatigue were grouped into three sub-categories: factors related to IBD, factors related to the individual, and factors related to health problems other than IBD (Table 8-1). The many sub-categories within each category are analysed in depth below.

8.2.1 Factors related to IBD

Factors in this category related to the process of disease and its symptoms, clinical tests and investigations, as well as to the medical and surgical management of IBD.

8.2.1.1 IBD, IBD activity and fatigue

All participants talked about their body not working properly as an effect of having IBD, and saw this as a direct reason for their fatigue: *'Fatigue as far as I'm concerned it's part of the whole thing, it's not quite by chance I just happen to be tired, I have colitis, if I didn't have one, I wouldn't have the other'* [Julie, UC, FL9]. Flare-ups and their severity were presented by some as a factor contributing to fatigue: *'My symptoms [are] flaring, so if I was having a lot of diarrhoea that would obviously increase my fatigue'* [Vicky, CD, FL8]. There seems to be a close bi-directional relationship between the severity of fatigue and IBD activity: *'When I'm tired, my Crohn's is worse, when my Crohn's is worse, I'm more tired so it's kind of cause and effect relationship'* [Vicky, CD, FL8].

Although most participants perceived disease activity as being in direct relationship with fatigue, this was doubted at times: *'I've always associated this fatigue with going to the loo, but whether I'm right or not, God only knows'* [Roger, CD, FL5]. This doubt may be influenced by the fact that some participants believed that IBD activity did not play a significant role in their fatigue severity. However, they believed that having IBD, and not necessarily its activity, was the main factor causing fatigue: *'Fatigue, tiredness, is virtually constant and that's irrespective of whether I'm having a flare up or not having a flare up. I've been flare up-free for so long and [I'm] still fatigued'* [Julie, UC, FL9]. Some participants may think that they are in remission, but their disease activity score may suggest otherwise as evidenced in Julie's case. Her UC score was 9 (score $7 \geq$ indicates severe disease activity), as assessed by the Simple Clinical Colitis Activity Index (SCCAI) (Walmsley et al. 1998).

Disease activity and the level of fatigue were assessed on the day of the interview and the results were compared for all participants (Table 8-2). It would appear that disease activity is not the only factor influencing fatigue severity; the most fatigued participants (fatigue scores 8-10) were distributed across all three (remission, mild and severe) disease activity groups.

Table 8-2 Disease activity and self-reported level of fatigue

Participant	Condition	IBD activity index**	Fatigue level*
In remission			
William	UC	4	4
Mark	CD	3	6
Robert	CD	3	4
Sue	CD	4	9
Mild disease activity			
Sophie	CD	6	6
Louise	UC	5	5
Laura	UC	5	6
Hugh	CD	6	8
Henry	UC	6	8
Alan	UC	5	10
Severe disease activity			
Andrew	UC	7	6
Vicky	CD	15	8
Catherine	UC	8	6
Fiona	CD	10	7
Roger	CD	14	5
Ruby	CD	9	7
Harry	CD	8	7
Sally	CD	7	8
Julie	UC	9	9
Gary	CD	7	8

Key: Fatigue level* - participants were asked to score their fatigue on the day of the interview on the scale of 0-10 with 0 = no fatigue and 10 = severe fatigue; CD - Crohn's Disease, UC - Ulcerative Colitis; IBD activity index** – in CD assessed using Harvey-Bradshaw Index (Harvey & Bradshaw 1980) and in UC assessed using Simple Clinical Colitis Activity Index (Walmsley et al 1998). Score of ≤ 4 indicates remission, scores 5-6 mild disease activity and score $7 \geq$ indicate severe active disease in both UC and CD.

Frequency of going to the toilet was often identified as a reason for fatigue: *'If I go to the toilet more often, obviously it makes the body work more, and having to go, producing more, then the body is more active so it seems to me I would feel more tired'* [Henry, UC, FL8]. One participant used the Bristol stool chart to explain the link between the stool type and her fatigue level: *'If my stools are not correct, then I know I'm going to be horribly tired. ... I've got a chart here – I call that a worm [type 4], if I go to the toilet in the mornings with those worms, I straight away feel this, my body, my energy is draining out of my body*

and the tiredness just overwhelms me. There are a few occasions when I do a normal stool I feel absolutely fantastic, my body's working, my brain's working, I'm alert' [Sue, CD, FL9].

8.2.1.2 Other symptoms of IBD and fatigue

Other IBD symptoms such as stomach cramps, abdominal pain, and vomiting were all mentioned as possible contributors to fatigue: *'Sometimes I feel like somebody's squeezing my bowel, really tight, and the pain is terrible and I can feel it rising up and making me feel sick actually ... I feel really worn out, really tired'* [Sue, CD, FL9]. Pain and pain severity were strong contributors to fatigue: *'I think my fatigue's increased significantly over the last few months, it's because the pain's been significantly worse. It's pretty much constant. ... If I can't breathe properly because the pain is that bad, my fatigue's 9 or 10'* [Vicky, CD, FL8]. Abdominal cramps and pain affected participants' sleep and that in turn affected their fatigue level: *'I can go to bed and fall asleep very easily, and it's not unusual to wake up within an hour or two because I've got discomfort in my stomach or it could be aches and pains in all my joints, in my neck, head, shoulders, all the way down. And they're not terrible but these aches and pains are just enough to wear you out'* [Gary, CD, FL8].

8.2.1.3 Iron deficiency anaemia and fatigue

Iron deficiency anaemia due to rectal bleeding and blood loss were identified by many participants as a cause of fatigue: *'I put it down to the fact that you have the blood loss that is why I thought I was tired'* [Catherine, UC, FL6]. Iron and vitamin B12 deficiency, because of dietary malabsorption were presented as contributing to fatigue: *'My B12 test, now it's a vitamin thing isn't it, is pretty low'* [Andrew, UC, FL6]. Some other participants talked about abnormal blood test results in more generic terms: *'I'm confident that the fatigue I suffer from is caused by some sort of imbalance of chemicals in my body'* [Mark, CD, FL6].

8.2.1.4 Clinical tests, medication and fatigue

Clinical investigations as well as medical and surgical treatment were all seen as contributing to fatigue. For some it was the investigations itself: *'Colonoscopy and a scan, it is tiring'* [Roger, CD, FL5] and for others it was the related stress: *'Going to the hospital and having my injections [Adalimumab] and blood tests stresses me out anyway, so I always feel tired afterwards'* [Fiona, CD, FL7]. Some questioned if the prescribed

medication for managing IBD, the dosage regime and side effects, was making them fatigued. Lack of compliance to treatment may have detrimental effects on increased levels of fatigue and other symptoms: *'I reduced one of my tablets [Azathioprine], only by 25mg, and everything was going fine, it was about 3 months that I was off of this 25mg and I'd started to feel unwell, I was having problems with my bowel, I was feeling not myself I really started going downhill and all I could do was lay on this settee during the day. Then the penny dropped in my head that it must be the tablet, so what I did that day was put the tablet straight back up again, so I was back on to my 100mg instead of my 75mg, but unfortunately it took another 3 months to get back into my system properly, and work properly'* [Sue, CD, FL9].

Not responding to drug treatment or having side effects were both identified as possible causes of fatigue: *'When I was first actually treated, I had a reaction to a drug, and everything went worse, I was really exhausted, it got to the point where I couldn't walk, I had to use a wheelchair just to get around because I was so tired'* [Fiona, CD, FL7]. The difficulty in establishing the correct type of treatment for the individual person was raised: *'I'm currently between a biological treatment or surgery, and I'm not really being told which one's better for me, and my concern is [that] either is going to cause an increase in fatigue because of what they're going to do to my body'* [Vicky, CD, FL8].

8.2.1.5 Steroids and fatigue

Steroids are often used in the acute inflammation stage to attain remission of IBD. Management by steroids was presented by some as improving the level of fatigue: *'When I was taking the steroids, I didn't feel fatigued, I was running around like a lunatic, that was lovely, I just want to do that again, just to have a couple of months where I run around like a lunatic'* [Ruby, CD, FL7]. However, for many, steroids were also the cause of fatigue as it affected their sleeping pattern and their circadian rhythm: *'When I was first diagnosed I was on steroid medication and that really affected my sleep pattern and I think that fed in quite a lot to my exhaustion and my general fatigue. I'd wake up and have energy at times like four in the morning when I should be sleeping, and I couldn't sleep but then at other times of the day, that was then knocking on the effect of my tiredness and fatigue where I'd then just be exhausted in the day time and wouldn't be able to function properly. So, I think the medication, especially the steroids had quite an impact on it'* [Laura, UC, FL6]. Long term side effects related to steroid use were also raised as possible contributors to fatigue: *'It could be the steroids, steroids impact healing and I've been on these for about 6 months*

which is too long, and I'm getting symptoms, side effects from that as well' [Vicky, CD, FL8].

8.2.1.6 Surgery for IBD and fatigue

Surgery and post-surgical recovery contributed to fatigue: *'The fatigue, after I'd had my operation, the first six months I was always tired because of the healing process'* [Sally, CD, FL8]. Multiple surgeries and associated recovery periods had cumulative effects on fatigue levels: *'I had surgery recently on an abscess and it's the fifth surgery and my recovery time for that was significantly worse than it had been in the past, and I felt fatigue was the most significant thing I struggled to recover from after that surgery compared to the last ones'* [Vicky, CD, FL8].

8.2.2 Factors related to the individual and perceived impact on fatigue

Factors related to the individual that affect fatigue and energy levels encompass age, body weight, diet, sleep, work and physical activity.

8.2.2.1 Age and fatigue

'Getting older' was perceived as affecting fatigue levels: *'I think, it must be something to do with the ageing process, the body gets less keen to do things and gets tired more easily'* [Henry, UC, FL8]. Hugh [CD, FL8] stated: *'As I've got older it's got harder to deal with [fatigue]'*. It is not clear if the ability to 'deal' with fatigue referred to physical or psychological aspects. Those who referred to the aging process (Hugh, Henry and Sally), were between the ages of 39 - 46. Therefore the term '*getting old*' or '*being old*' reflects their subjective perception of age, rather than their actual chronological age. It is worth noting that all three participants were single at the time, and two (Hugh and Henry) had no children. Hugh and Henry both expressed regret that they did not have a family. The oldest study participant, Robert, was 82 years old, married, with children and grandchildren, but did not perceive his age as having impacted his fatigue levels: *'I'm only 82 on a calendar, 82 on my knees and 28 up there [pointing to his head]'* [Robert, CD, FL4]. This would imply that age measured in calendar years may have less impact on individuals' perception of 'being old'. This subjective perception of age and 'being old' may have a negative impact

on how participants see themselves, and it may stop them from being positive and proactive.

Young age was also identified by some as contributing to the fatigue level: *'I was first diagnosed when I was really young [12 years old], go back to that, how exhausted I was not being able to physically get off the settee as a young teenager, you'd probably put it down to being a teenager as well, can't be bothered'* [Catherine, UC, FL6]. Fiona was diagnosed with CD when she was 17 years of age, and she explained her experience: *'I remember feeling tired and coming home from school and being too exhausted to work'* [Fiona, CD, FL7]. Age alone does not seem to provide a full explanation for fatigue severity. It is most likely a combination of factors that has a more severe effect on participants' energy levels. Further discussion of multiple factors and their impact on fatigue is presented later on in this chapter.

8.2.2.2 Body weight and fatigue

A few participants thought being either over- or underweight added to their fatigue level: *'I thought it was me carrying too much weight, and I just put it [being fatigued] down to that'* [Catherine, UC, FL6]. A participant who had lost weight due to intestinal abscesses necessitating multiple surgeries, said: *'I was very underweight. ... My weight was about seven and half stone in all, so it was very difficult then to have the energy to get on with life in general'* [Hugh, CD, FL8].

Those on steroid therapy presented a more complex picture in terms of gaining weight and how it affected fatigue: *'I was a size 8 with kind of 12% body fat before I had Crohn's, and now I'm definitely not a size 8 and I've got more body fat ... but I'm too fatigued to exercise'* [Vicky, CD, FL8]. Andrew thought that his energy levels were low as a result of muscle atrophy: *'I have noticed in the last 2 or 3 months that I'm losing the muscles in my arm. ... What I understand [is that] the body, rather than taking goodness out of the food, it feeds itself off your muscles'* [Andrew, UC, FL6]. It would appear that body weight and the muscle and fat ratio played a part in the level of reported fatigue.

8.2.2.3 Diet and fatigue

Diet was identified as a reason for fatigue. Some participants talked about not having regular meals and not eating a balanced diet due to IBD: *'If I could have eaten a more balanced diet, then maybe I might feel better, have more energy'* [Sophie, CD, FL6], while

others expressed concerns about their ability to absorb nutrients properly: *'I don't process food effectively so, obviously not getting what I need out of that. If I could have a better diet I would feel less fatigued'* [Vicky, CD, FL8]. Low intake of calories was mentioned by some: *'I am pretty convinced it's diet based, and I'm pretty convinced if I, you know, anyone that's eating less than a thousand calories a day isn't going to have energy'* [Julie, UC, FL9].

Some participants identified specific groups of food (e.g. carbohydrates, dairy products, red meat, vegetables and fruit) as causing significant abdominal pain and contributing to more severe fatigue: *'If I eat what I think is a normal healthy diet for example whole-wheat bread, wholegrain food, fruit, you know apples, apple skins, bananas, there are certain food types that make me worse without a shadow of a doubt. For example, if I had a bowl of Weetabix, or Shredded Wheat or bran flakes or porridge even, brown bread, wholemeal bread, cake, biscuits, pastries, anything like that, it annihilates, and I mean annihilates me'* [Harry, CD, FL7].

Consuming any food was reported by two participants as directly contributing to their fatigue: *'If I go for long periods and avoid food I'm fine, once I have something to eat, and it can be a small sandwich or a bowl of soup, it takes, sometimes it's 20 minutes, before you can feel the fatigue creeping in'* [Alan, UC, FL10], so they see food consumption and food digestion as an enemy. Others also talked about the influence of alcohol on their fatigue: *'I can't drink alcohol any more ... I lose all my energy'* [Mark, CD, FL6].

8.2.2.4 Sleep and fatigue

The amount of sleep, and sleep quality were frequently mentioned: *'Possibly it's as much to do with lack of sleep. I mean normally it's not more than 6, 6 and a half [hours], so I'm definitely getting less sleep, but even when I did get more sleep, like at weekends, I was still tired and fatigued, so it didn't really sort of help'* [Henry, UC, FL8]. However, excessive amounts of sleep had equally negative effects on fatigue: *'I can have situations for example, where I've slept for 10, 12, 14 hours and I come downstairs and I haven't got the energy to do anything'* [Harry, CD, FL7]. Poor quality of sleep had a negative impact on fatigue: *'There's an issue with you not having the right kind of sleep, so if you don't get that REM sleep there are certain chemical reactions not going on in your body so your body does not restore itself properly at night'* [Gary, CD, FL8].

The link between fatigue and other factors (e.g. sleep, disease activity, pain, steroids and having to get to the toilet at night) was discussed by participants: *'I don't sleep too well, partly because I'm sleeping a lot during the day because of the fatigue, so I don't really sleep, I go to bed at night, I'm up and down all night'* [Alan, UC, FL10]. There appears to be a cyclical relationship between having to nap during the day, as a way of coping with fatigue, and as a result not being able to sleep well at night, resulting in more severe fatigue.

8.2.2.5 Physical activity, work, daily routine and fatigue

The level (intensity and duration) of physical activity, work and daily routine were frequently identified as direct causes of fatigue: *'I think it's [fatigue is] also a sign of when I've probably been doing a bit too much and pushing myself too much'* [Laura, UC, FL6]. Some may not have fully understood the link between leading a busy life and fatigue: *'The fatigue up to a point, might be as a result of doing too much, I think, I hadn't really considered it in those terms before, but I might be doing too much'* [William, UC, FL4]; others, despite being aware of the link, decided to continue with their activities: *'Most of the time now I can work out why that is [being fatigued] – I've overdone it the day before, but I still do it'* [Mark, CD, FL6].

This 'over-doing' of things, was at times related to a large amount of work and having to meet deadlines. At other times, because participants were not able to do their normal activities for a period of time due to fatigue, they knowingly overdid certain activities when they felt energised, just to compensate for the days when they were not able to do much: *'When you have a good day, you do a lot, you do too much. I overdo and then unfortunately because you've done so much in one day the next day I'm so, so tired'* [Sue, CD, FL9].

Some considered if their established routine caused fatigue: *'I've wondered whether it's because of the routine that I have at the weekend, I do the housework on a Sunday, the ironing, the cooking, I have thought whether it's because I'm doing all this stuff on one day that's making me knocked out the next'* [Sophie, CD, FL6]. Others talked about how their reduced physical activity contributed to them feeling more fatigued: *'The less you do, the less you feel like doing'* [Laura, UC, FL6]. Lack of motivation and negative attitudes are further discussed later in section 8.3.

It appears that participants may not always be able to change their activities and thus prevent worsening fatigue; however, recognising that certain activities may lead to more

severe fatigue, some did not necessarily change their behaviour as they wanted to be in control of their lives.

8.2.3 Factors related to other health problems and perceived impact on fatigue

Health problems, other than IBD, were identified by some participants as affecting their fatigue. Problems such as irritable bowel syndrome (IBS), underactive thyroid, sleep apnoea, and depression were mentioned: *'I've got other things wrong with me which cause fatigue. I've got irritable bowel disease, I've had problems for years with chronic depression'* [Alan, UC, FL10]. Rheumatoid arthritis, joint pain and fibromyalgia were identified as adding to fatigue severity: *'I always seem to be more exhausted when my arthritis and my Crohn's is bad'* [Fiona, CD, FL7].

Some participants talked about their long term conditions and fatigue. Sophie, diagnosed with CD less than a year ago, said: *'I get seasonal affective disorder and I've got depression which I've treatment for. ... Other illnesses I've mostly had them for some time, and they're under control, and they don't bother me, but obviously this [CD] is a big one'* [Sophie, CD, FL6]. She was diagnosed with other health conditions for a much longer period than with CD, and she feels that she is able to cope better with her other health problems, and therefore sees CD as the main cause of her fatigue. Alan, diagnosed with UC less than a year ago, has diabetes: *'The diabetes has its own issues with fatigue, and all the issues that revolve around the diabetes, because it's controlled with medication as well as diet, so there's a lot of things overlapping'* [Alan, UC, FL10]. For Alan the best way to avoid fatigue was to avoid eating, however he needs to eat regularly because of diabetes, so having diabetes seems to indirectly add to his fatigue severity. Andrew, diagnosed with UC over 8 years ago, has had chronic obstructive pulmonary disease (COPD) for a long time: *'I've been diagnosed with COPD, which in itself is a bit tiring, and I've been asthmatic all my life, but I haven't had an asthma attack for 10 years now, so I don't think, it might be affecting me a little bit, but it's nothing, it's not affecting me any way as near as this [IBD]'* [Andrew, UC, FL6].

Despite having other health problems, participants perceived IBD as the dominant cause of their fatigue. It would appear that some factors were perceived by the participants to have a direct, causative impact whilst other factors were perceived to contribute to the cumulative effect of fatigue.

8.3 Psychological contributors to fatigue

Participants identified stress, anxiety and depression and negative frame of mind as contributors to fatigue.

8.3.1 Stress as a factor affecting fatigue

Participants verbalised the direct relationship between stress and fatigue: *'If my stress will go up, my fatigue gets worse'* [Fiona, CD, FL7]. Some people were less able to cope with everyday stressful situations and consequently seemed to use more energy or get more stressed which resulted in them getting more fatigued: *'I've had trouble with the digital changeover, I've had trouble with the bank, and I've had trouble with the garage ... so it affected, because you know, worry and stress, they say it doesn't affect you but I know it does. I was being sick as well sometimes, I was totally exhausted'* [Andrew, UC, FL6].

8.3.2 Anxiety and depression

Anxiety had a direct link with fatigue: *'You get anxious and worked up about what's coming up, and that I think has a physical effect on you'* [Hugh, CD, FL8]. A few participants thought that they had a tendency to worry: *'I seem to be a kind of anxiety prone person, it makes me more tired'* [William, UC, FL4]. Depression and low mood were also identified as direct causes of fatigue: *'When I've been very morose I felt more tired'* [Roger, CD, FL5]. Those participants who talked about depression and low mood were very keen to stress the difference between the two: *'Low mood, I'm low in mood, I'm not depressed, that gets me very tired'* [Sue, CD, FL9], and Gary said: *'I am depressed, not clinically depressed, I know the difference because I used to be depressed in the past, now I am low mood and that makes me more fatigued'* [Gary, CD, FL8].

Participants also identified a challenge in terms of the direction of the relationship between fatigue and depression; for some depression was a cause of fatigue, for others it resulted from fatigue, but often it was both: *'The depression, there's obviously overlaps between the fatigue or the tiredness that might come from depression, and Crohn's'* [Hugh, CD, FL8]. Most participants were in agreement that low mood directly influences their level of energy. Catherine questioned if her antidepressant medication additionally contributed to her fatigue severity: *'I'm on tablets for anxiety and depression at the moment, so I don't know whether that's calming me down too much'* [Catherine, UC, FL6].

Julie however had the opposite view: *'It's [fatigue] not mood dependent, because I'm a fairly happy mood all the time. ... It is the other way round, it's not – my state of mind, my state of mind does not dictate how tired I am, sadly'* [Julie, UC, FL9]. Anxiety and depression were seen as direct contributors to fatigue by most of the participants, however there were also opposing and contradicting views, as presented by Julie, where anxiety and depression were the outcomes of fatigue.

8.3.3 Negative frame of mind and negative feelings

Not being able to prevent fatigue and seeing themselves as being out of control made some people more frustrated and angry, and therefore more fatigued: *'There is nothing people can do about it, there's nothing you can do to help, and that makes me frustrated and tired'* [Fiona, CD, FL7]. Many participants identified the distress of dealing with IBD, the diagnostic tests and procedures for monitoring and managing the condition as directly linked to fatigue: *'I go for x-rays, and blood tests all the time you know, because they bloody sound as though these tablets are dangerous you know, so you know what's my blood test, must be alright, we will tell you if it's wrong you know, well that's no way is it. All these things compound. ... You feel so useless, it's terrible, and tired'* [Roger, CD, FL5]. The restrictive nature of IBD caused frustration and stress which in turn added to feeling fatigue: *'The frustration of not having the freedom of being able to just get up and go out, you've got to think, I better not eat anything, I've got to take tablets before I go out, you know, is there a toilet between here and the bus stop? Will the church be open? I can nip into the church if need be. So all this is constantly going through your mind, so all that must be quite exhausting in itself, all these thoughts'* [Catherine, UC, FL6]. A negative frame of mind is linked to the uncertainty related to the unpredictable and chronic nature of IBD leading to distress: *'I felt absolutely terrible physically, and psychologically you were thinking, well is this it? You know, am I ever going to get better basically, am I going to be like this forever?'* [Mark, CD, FL6].

Some participants felt that their personal situation exacerbated fatigue. This was often related to family and personal problems: *'Three and a half years ago my parents both died, only two weeks apart. My Dad had Crohn's, he got diagnosed in his early 20's but he nearly died because of it, and he had to have surgery. My Mum's sister got Crohn's, she needed to have surgery so as you can imagine that's like, oh my God, that I've got all this stuff going on round my head and I'm thinking, you know I'm just trying to make sense of things, because my head's still swimming with it all'* [Sophie, CD, FL6]. This negative feeling

impacted on participants: *'My physical wellbeing has an impact on my mental wellbeing, and my mental wellbeing has an impact on my physical wellbeing'* [Sally, CD, FL8].

8.4 Cognitive contributors to fatigue

Amongst cognitive factors, only mental activity (having to concentrate over a prolonged period of time) was discussed: *'I can't concentrate too long on reading and things, that makes me more tired'* [Sophie, CD, FL6]. A combined effect of physical and mental activity was raised: *'I find I am suffering more with fatigue, just because I'm physically doing more and mentally doing more'* [Vicky, CD, FL8].

8.5 Situational contributors to fatigue

Environmental factors, a lack of support, and a lack of understanding of fatigue by individuals themselves as well as by health professionals were reported as situational factors contributing to fatigue.

8.5.1 Environmental factors and fatigue

Environmental contributors, such as weather extremes (hot and cold temperatures, windy weather, snow and the level of natural lighting) were reported as impacting on fatigue: *'I get seasonal affective disorder, [so] winter is really bad for me because I've got the fatigue twice fold'* [Sophie, CD, FL6]. Some reported cold, windy weather as affecting their fatigue: *'Going out in strong winds, definitely has an effect, going out in the cold is also another thing that makes me tired'* [Robert, CD, FL4], while others were affected by heat: *'I can't deal with heat or cold, heat particularly, I mean the summers are, if the temperature gets above about 22-23C, I'm virtually passed out in a chair. I just can't deal with heat at all'* [Mark, CD, FL6].

Cold weather had an indirect impact on Sally's fatigue: *'It's cold now, so if my stomach's not covered up and kept warm, if my stomach gets too cold, that's it, I've got to go to the toilet'* [F18, CD, FL8]. Cold weather acts as a trigger for increased bowel activity, which leads to an increased anxiety level, partially related to being in public place (as presented earlier) and lack of control, and this in turn results in a greater level of fatigue.

8.5.2 Lack of support and fatigue

The type, quality and level of support, was frequently mentioned as a factor contributing to fatigue. The type of support needed, expected or required by participants ranged from information to practical help, and was related to the diagnosis of IBD and its symptoms, and/or the participants' inability to deal with daily activities as a result of IBD and fatigue.

Some reported not having sufficient information and understanding of IBD and fatigue made them struggle to cope, which in turn contributed to more severe fatigue: *'Having the Crohn's, having the operation and then developing the fatigue, nobody warned me that that could happen; I got the diagnosis, given medication, off you go, get on with it. I never got told that this would happen, I never got told it was an autoimmune system disease, that it could affect my body from head to toe, not just my bowels. I never got told that I end up having bowel surgery, never got told that I could end up having a stoma, never got told that I could put weight on'* [Sally, CD, FL8].

Loneliness and not having help and support from anyone affected fatigue. The unpredictable and undesirable nature of IBD made people even more isolated: *'I'm a grumpy old man sitting here on my own you know'* [Andrew, UC, FL6]. Catherine, a single parent, said: *'I've got a twelve year old [daughter] that's completely dependent on me. ... I'm not having a great time just now. I have no energy.'* [Catherine, UC, FL6]. Many participants had no, or a very limited circle of friends: *'Friends-wise, I can count on one hand, so yeah, I've got [husband] mainly'* [Sophie, CD, FL6].

Sue, a housewife, who despite her husband's support put great pressure on herself, as she felt responsible to contribute to the household: *'It's only me and my husband, he goes out to work, I stay at home and do all the work, jobs ... and I get told this, my husband said it doesn't matter if the ironing doesn't get done, and I say yes it does because it will get too dry, I've got to do it you know'* [Sue, CD, FL9]. Vicky, who also has a supportive partner, tried to explain the complexity of the situation: *'I feel guilty that people have to support me – one thing that was always really important to me, was being independent, being able to do things for myself when I wanted, how I wanted. I don't really have a lot of independence, it often relies on other people and considering how I'm going to impact them and how they can support me, and I would prefer to be supporting them than being supported myself'* [Vicky, CD, FL8]. Accepting help and support from others, while being unable to reciprocate that support, was a source of guilt that created greater sense of fatigue.

Lack of support and understanding from employers in relation to IBD and fatigue was mentioned: *'When a manager took away the gents toilets in our department and we then had a generic male and female toilet – I didn't even want to go there and that was it, that was me finished. There was no support at all, so they sacked me'* [Harry, CD, FL7]. Any fatigue-related absence was not understood by most employers: *'There is a culture there that they kind of assume that you're just skiving off or you're making more of it than it actually is. So, I'm saying that there's a sick note here that said fatigue, and I give that and I've, from feedback from other people that have told me what managers have said, and they look at it and they think, what's that, that doesn't mean anything, that's just, he's tired and he wants a week off so that again adds more pressure'* [Hugh, CD, FL8].

Healthcare professionals were criticised by many participants for not understanding fatigue and not listening to participants' concerns. Some participants had tried several times to communicate the message about their fatigue: *'They [healthcare practitioners] are not listening to me, and the bigger picture of how my life's impacted. So, I'm frustrated that there isn't the acknowledgement and there isn't the support. I feel like I've been banging my head against a wall for years, because it's relevant it's what I have to live with, and I think it's part of the illness'* [Harry, CD, FL7], while others have become resigned to not being listened to and just being ignored: *'There's no interaction with me as an individual, their interaction is with my Crohn's and if my Crohn's doesn't talk to them, they're not interested. If the blood tests don't show x, y and z, they're no longer interested ... [so] I'm not angry, not any more, I've gone past this I think, as I say I just tend to ignore them really, they're there if I need an operation is the way I look at it now'* [Mark, CD, FL6].

Sue was referred to a psychiatrist when she tried to explain her fatigue: *'I was feeling very unwell and I went to see my consultant, and I said 'oh I just feel so tired ... I feel a bit like a zombie' and I think because of the terms I used, he said 'I'll send you to a psychiatrist', and I hadn't got the energy to fight back, I really hadn't. And I felt annoyed but I was too tired to even think about it anymore, so I left there and I was very unhappy, and I said to my husband he wanted me to see a psychiatrist, and I don't need a psychiatrist, I'm just tired, because my bowel isn't working properly. I think I've learnt not to talk about the tiredness anymore. I don't think they understand'* [Sue, CD, FL9]. Healthcare professionals (HCPs) were seen as not fully understanding fatigue: *'The fatigue and what causes it, I've never been given answers to that because I don't think they know. ...The way I look at it is if my gut is in remission, and the inflammation is not so bad, why am I still affected by the fatigue'* [Alan, UC, FL10].

8.5.3 Lack of knowledge and understanding of fatigue by participants

Some participants were not aware that fatigue could be part of IBD or they had a lack of understanding of fatigue: *'I didn't actually relate it [fatigue] to my IBD at all'* [Catherine, UC, FL6], and others worked it out for themselves: *'As the colitis got worse, the fatigue's got worse so, now I realise it was part and parcel of it, but at the time I didn't realise'* [Louise, UC, FL5].

Some participants had no explanation as to why they were fatigued. To a question *'Is fatigue related to anything?'* Ruby replied: *'No, I feel like it's [fatigue] there all the time'* [Ruby, CD, FL7] and Vicky said: *'Sometimes I don't feel like there is a significant predictor, I've got no idea where it's [fatigue] come from'* [Vicky, CD, FL8]. This lack of understanding and the unpredictable nature of fatigue add to the level of stress, and indirectly to the level of fatigue.

Participants tried, often unsuccessfully, to identify causes of their fatigue: *'I may not be having a particularly bad day with my joints or my colitis but I will just feel generally tired and I suppose maybe some of my mental concentration will go, even without the flare'* [Laura, UC, FL6]. The inability to clearly link certain factors to fatigue left participants feeling powerless, frustrated, and more fatigued.

8.6 Interrelationship between different factors and fatigue

The complex interrelationship between factors and their impact on fatigue varied between participants. For some, factors contributing to fatigue were predominantly physical: *'If I don't eat solid food I feel pain-wise, better, but exhausted. If I eat normal food, I feel some more energy but I'm in so much pain that there's no point having more energy. So to that extent I choose tiredness over pain'* [Julie, UC, FL9]; for others it was a combination of factors from all four categories (physical, psychological, cognitive and situational): *'If my symptoms are bad that affects me sleeping, so then obviously that affects my fatigue ... A lot of my sleep is disturbed because of anxiety and stress, particularly at the minute with concerns over my treatment, that's causing me a lot of problems in terms of sleeping'* [Vicky, CD, FL8].

For many participants stress, depression, anxiety and fatigue and dealing with IBD symptoms were all linked in a perceived chain of events: *'I would find that the depression would then kick in once the bowel said right we've finished, my mind would say OK right now you've got to deal with that and so it would just go round and round and round, and I think that in itself, with the tiredness, makes you even more run down and exhausted just dealing with it'* [Hugh, CD, FL8].

Some factors had a direct and others an indirect impact (chain of events) on fatigue. Different factors from all four categories could be classified as direct or indirect for different participants. A causal network of the factors identified to relate with fatigue and the relationship between them is presented in Figure 8-1. The causal analysis used a constructivist, inductive approach to determine and depict relationships between factors and fatigue (Miles & Huberman 1994). This process involved listing and grouping the factors identified as related to fatigue. Then, a line was drawn between the factors identified by the participants as having a relationship, and finally a directional arrow was drawn showing the temporality of influence between factors.

Creating the causal network of factors helps to visually demonstrate the complexity of the relationship between the factors (Figure 8-1). This suggests that the assessment of factors and the impact on individual's fatigue should take place at an individual level. It is possible that the effect of multiple factors on fatigue severity is much greater than the impact of single factors; however this was not explored directly. Several factors (e.g. steroids, infliximab, sleep, diet and exercise), were presented as having both a positive and a negative impact on fatigue for different participants, and some of them were also used to manage fatigue. These are discussed later in this chapter – the methods of managing fatigue.

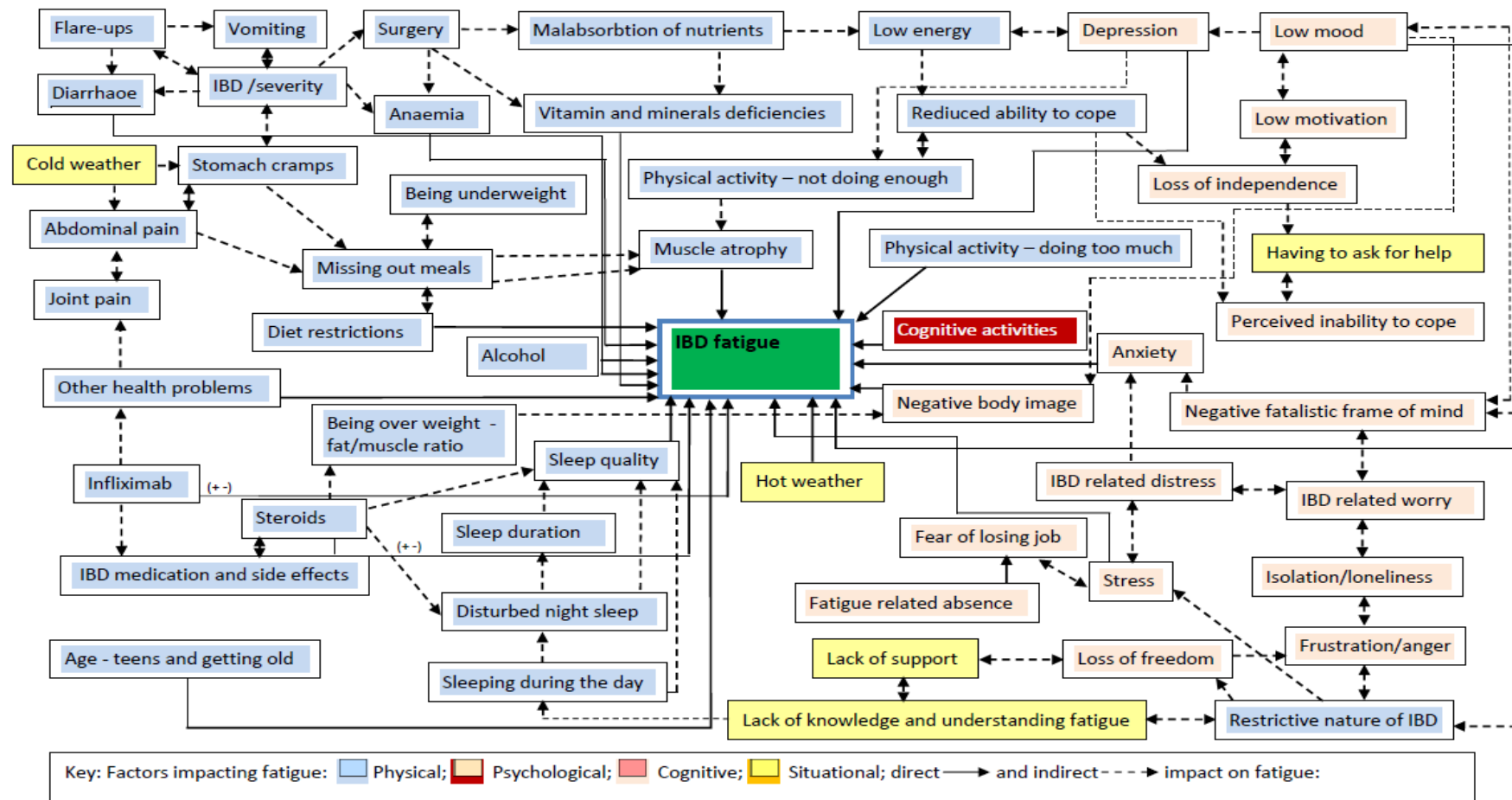


Figure 8-1 Causal networks of factors reported as impacting on IBD-fatigue

8.7 Methods used by individuals with IBD to manage fatigue

The first part of this chapter covered the contributors to fatigue. The remainder of the chapter presents the methods used by participants to combat fatigue. Some participants questioned whether fatigue could be effectively managed: *'I don't know if I have a lot of things to help myself with fatigue'* [Catherine, UC, FL6]. Methods of managing fatigue were grouped into four categories: physical, psychological, cognitive and situational (Table 8-3).

Table 8-3 Methods tried by participants to manage fatigue

Physical	Psychological	Cognitive	Situational
Diet	Stress management and reduction	Cognitive behavioural therapy	Support physical and psychological
Pacing and energy management	Motivation and positive attitude	Change of activities	Information and education
Night time sleep	Counselling	Being in control	Forward planning
Physical exercise	Prioritising		
IBD management			
Vitamin and mineral supplements			
Alternative therapies			

8.8 Physical methods used to manage fatigue

The participants identified many different physical methods that they have tried in their attempts to manage fatigue. The methods most frequently talked about were diet, night time and day time sleep and rest, energy management (e.g. taking regular breaks and pacing) and physical exercise. Other methods were also talked about but to a lesser extent: IBD management, taking vitamin and mineral supplements, alternative therapies and using a combination of different physical methods.

8.8.1 Diet

Small and frequent meals were seen as a way of keeping energy levels steady: *'Little, but often [food consumption], which is a Crohn's thing anyway, it helps the energy going'* [Mark, CD, FL6], and: *'I have rice or the wheat free pasta, that are slow burning carbs to keep my energy level up'* [Sophie, CD, FL6]. Some participants avoided food known to upset the digestive system: *'I mean breakfast is the main problem because I end up having sugary cereals because they've not got any wheat in them like cornflakes and Rice Krispies, and just manage to introduce a little bit of wheat free granola in to give it a bit more bulk'* [Sophie, CD, FL6], or avoiding food for as long as possible: *'If I don't eat anything at all I feel a lot better, but I can't survive without eating food'* [Harry, CD, FL7].

Diets high in carbohydrates were reported to be effective: *'I started eating more carbohydrates, got more energy. ... That was a really simple thing that made a lot of difference; it didn't make total difference but it made a lot of difference'* [Julie, UC, FL9]. Caffeine and high energy drinks were used with varied effectiveness: *'I have to drink caffeine throughout the day, usually Coke because coffee doesn't seem to have the same effect on me'* [Sophie, CD, FL6], and: *'If I have a full bottle, the big bottles of Lucozade, if I have one of those throughout the day and just keep sipping on it, I can maintain myself and get through a full day without feeling overly tired'* [Sally, CD, FL8]. However some participants questioned the effectiveness of high energy and caffeine products: *'I did try once taking some glucose, I bought some glucose powder, and I thought, I wonder if that will help the tiredness, and it didn't and I was ever so disappointed'* [Sue, CD, FL9]. A variety of different food and drink products were reported as effective in managing fatigue but they did not work for all. The most effective seemed to be small and regular meals. It would appear that for some participants, food digestion and certain types of food would exacerbate gastrointestinal symptoms, leading to more severe fatigue. Unfortunately, as the participants themselves said, not eating is not an option long term.

8.8.2 Pacing and energy management

Participants took frequent and regular breaks to *'recharge their batteries'* and paced themselves to make sure that their energy would last a little longer: *'When you're tired you do need to have a rest at some point later in the day'* [Louise, UC, FL5], and combining a break with food intake seemed to be effective: *'I work in a team where everybody stops for*

twenty minutes to have some lunch, so I've got into a pattern of doing that and that helps [with fatigue] ' [Gary, CD, FL8].

Frequency and the length of breaks varied between participants, depending on how much flexibility they had during the day: *'I don't obviously get opportunity here [at work] to have a nap although I think sometimes it would probably help, even just a little power nap of 15 minutes'* [Sophie, CD, FL6].

Participants who did not work had more flexibility in terms of time management and would have longer or more regular breaks during the day to relax: *'Mid-afternoon, I can get that whole hour of unbroken sleep, and that does definitely help, I feel somewhat restored when I wake up'* [Robert, CD, FL4]. Just resting was equally beneficial: *'Usually I will rest in the afternoons, I will either just sit or I will lie down on the settee for about half an hour just to give myself the energy to carry on, that's the only way I can cope with it'* [Sue, CD, FL9]. However, taking such breaks was also seen as negative, a waste of time doing nothing, not conforming to expected norms of adults being busy during the day: *'I feel guilty if I spend a day lying on the sofa, that's hard not to feel guilty and think you should be doing something'* [Ruby, CD, FL7].

The effectiveness of taking breaks when fatigued was questioned by some participants: *'I know that simply the amount of time spent lying and doing nothing will give me some energy, however much it will give me I don't know'* [Julie, UC, FL9]. For some, a reduced level of activity was not very effective: *'In the afternoons I just don't do a lot, but it's [fatigue] not getting any better'* [Roger, CD, FL5]. There was a lack of clarity in terms of the balance between rest and activity: *'I've done things where I've stayed at home all day and just rested, and it's made no difference to how I feel the next morning'* [Sally, CD, FL8]. All participants reported that taking a break or having a nap would partly help them to manage fatigue, however they would never feel fully rested, and the amount of regained energy varied between people. Often the amount of regained energy was not proportionate to the duration of rest.

8.8.3 Night time sleep and rest

Night time sleep, its duration and quality helped reduce fatigue and restore energy for some: *'Sleep's the only thing that's going to resolve that [fatigue]'* [Vicky, CD, FL8]. However, participants did not feel fully refreshed after night time sleep: *'I sleep well, it's not often that I don't manage to sleep OK; last night I had about eight hours sleep, quite good sleep.'*

That's been the case for a few weeks, I sleep quite well, quite deeply, but I'm still tired' [William, UC, FL4]. Participants could not predict how many hours of sleep would be sufficient for the desired effect of feeling refreshed.

Some, who experienced a sleeping problem, resorted to taking medication to help them be more refreshed, either prescribed: *'I take Amitriptyline to help me sleeping'* [Gary, CD, FL8], or over the counter: *'I take some herbal tablets called Quiet Life to help switch the head off because otherwise I have all sorts going round and I'll never get to sleep'* [Sophie, CD, FL6].

Sleep duration and having a choice when to get up in the morning was perceived to help with fatigue: *'If I feel tired in the morning then I will stay in bed that little bit longer, not force myself to get up, because I've found that doesn't work either – people say keep to a strict timetable, but if you get up, if you're still feeling tired, that extra hour can help you start the day smoothly'* [Louise, UC, FL5]. Those who worked full time did not have the same flexibility: *'I know generally I'm going to be better at weekends because I can have that lie-in, I don't have to be up at a certain time, I can wake up more naturally than to an alarm'* [Vicky, CD, FL8]. Some participants, who thought that they were not getting enough sleep to reduce fatigue, did not change their habits: *'I manage to usually get about seven hours sleep or thereabouts, maybe a bit more. Maybe I ought to make it a habit at getting to bed at say 10 o'clock at night and sleeping till whenever, but I never seem to get around to doing that, so maybe I should do that'* [William, UC, FL4].

Longer sleep as a remedy for fatigue was contradicted by some participants: *'I can sleep 10, 12, 14, 16 hours, I can come downstairs and I can then be asleep for another 2, 3 hours, it's unbelievable how tired I am, and weak at the same time. ... So sleep doesn't really help with fatigue'* [Harry, CD, FL7].

8.8.4 Physical exercise

Physical exercise was used to build stamina to manage fatigue. The range and the duration of activities varied between participants, from getting off the bus one stop early, to gentle exercise or swimming: *'I was trying to go three times a week swimming, normally once at the weekend and twice during the week just to try and keep myself going'* [Laura, UC, FL6].

Participants were uncertain of the type and the duration of exercise they should be doing to achieve the positive effect of strengthening muscles and building stamina, and not to

exacerbate their IBD symptoms: *'I think, a certain amount of exercise does help, but it's knowing where to draw the line'* [Hugh, CD, FL8]. Exercise however, was not seen as positive by all: *'I went down to the GP and I told him about all fatigue and this wastage in my arms [muscle atrophy], and I was feeling absolutely awful and I'd got some diarrhoea, and he gave me a prescription to go to the health centre down the road to go for a course of exercises. I mean you know, come on, not a very good GP is he'* [Andrew, UC, FL6]. It appears that some participants would prefer their medical problems to be given a medical treatment, and not a physical activity which was not seen as a treatment.

Only a few participants took a regular and systematic approach to exercise and reported positive effects on having more energy: *'I've been doing these little exercises. It sounds daft but it is working, and I'd recommend anyone else who is really tired. I've dug up this old sheet from when I had bad back, so I've been doing them, but not many of them, but some of them, because I'm sure, I'm absolutely certain that it did help, and does help'* [Roger, CD, FL5]. Roger also talked about how successful and effective the exercises were in terms of having more energy: *'By doing these little bits of exercise, I can now walk three miles, I couldn't do it June, July, I couldn't do it then. I've been doing them for about three months, two or three months – and I only do sit ups and these mild press ups but I don't do many, but it just seems to help, and I want to do more and more of them, longer and longer. I'd like to do it for half an hour'* [Roger, CD, FL5].

It took some participants longer to change their attitude towards exercise: *'When it [fatigue] first sort of came along and hit me, some of the things like, pacing yourself, and graded exercise – utter rubbish. But after a while, you begin to think, oh perhaps there is some; because you don't see that as treatment, as alleviating anything, just go for a ten minute walk and then next week go for a twenty minute walk and you think, utter rubbish, but actually when you start doing it, you realise that it really does help'* [Mark, CD, FL6]. Elsewhere Mark adds: *'Well, yes in the sense that it talked about graded exercise and pacing and that sort of thing, but at that time I don't think I was ready to take that on board. But when it was suggested to me later, I had some back knowledge – I remember reading about that, perhaps there's something in that after all'* [Mark, CD, FL6]. Some perceived exercise as beneficial physically and mentally: *'I did karate for two or three years, and it was useful for me because I could do it straight after work, and although yes it obviously did make me very tired, it did help I think with my attitude to things'* [Hugh, CD, FL8].

It seems that some participants perceived exercise as general activity and not a treatment for fatigue. For others, the advice regarding exercise as a method of managing fatigue was not sufficiently specific or tailored to their needs and they did not perceive it as likely to be effective. Only a few participants changed their attitude regarding exercise, having a higher level of motivation and commitment to take up or continue with exercise, and saw its beneficial effects on fatigue.

8.8.5 IBD management

The management of IBD and related symptoms was frequently mentioned as a direct cause of fatigue, but interestingly not many participants talked about controlling IBD as a way of managing their fatigue. Some participants, who were in relapse, or newly-diagnosed who did not have an established maintenance therapy, accepted that fatigue will resolve itself, when IBD is under control: *'I've discussed it [fatigue] with my nurse, she's very good, and explained that I am very tired and it is affecting me, and she's recognised it, but obviously what she's kind of saying is that until my symptoms are settled, it's not really the primary worry, because while my symptoms aren't settled, I've got a lot more pressing concerns, and hopefully once those are settled my fatigue will be decreased'* [Vicky, CD, FL8].

Having access to a consultant or to an IBD nurse via a helpline at the time when IBD symptoms, including fatigue, were deteriorating was seen as beneficial. Some participants were self-managing their symptoms: *'I have an agreement with my doctor, and actually even the hospital now are relatively happy with it – if the Crohn's rears its head, two weeks of steroids, because that's the kind of knock it on the head type of thing, which I give myself, if that doesn't sort it out, then I go to the doctor or the hospital'* [Mark, CD, FL6].

Some participants tried to be proactive in managing their IBD but experienced considerable obstacles within the NHS system: *'I've spent two years begging them to let me see a nutritionist, because I'm convinced if I can see somebody who will talk through with me, the specifics what I can and can't eat, I would have more energy, because I've tried it myself and sometimes things work, sometimes things don't work. ... They keep fobbing me off, because seeing a dietician apparently is harder than seeing a surgeon'* [Julie, UC, FL9].

8.8.6 Treating vitamin and mineral deficiency

The benefits of taking vitamin and iron supplements to improve fatigue was reported with varying success: *'I keep up with my iron liquid, because I'm on iron liquid for the anaemia'* [Louise, UC, FL5], and Mark said: *'The B12 injections were like a dose of energy, I mean I had the six injections over the space of two or three weeks and at the end of that I mean, I was almost a different person'* [Mark, CD, FL6]. This opinion was not shared by others: *'I took vitamins, I was taking Vitamin A-Z, I was taking evening primrose oil, I have to take calcium supplements because I'm on the steroids, I was taking iron tablets before, none of it really helped to be honest. ... I took them for about two months and then I don't really take them any more'* [Vicky, CD, FL8]. Some had very negative opinion about supplements: *'I've tried like taking vitamin supplements, iron supplements, waste of time, waste of time'* [Alan, UC, FL10].

Discrepancies between accepted normal levels of ferritin advocated among HCPs in different countries were causing confusion: *'There seems to be a big difference of opinion between the American establishment and over here [UK] as to what your ferritin levels should be to start with, in that in America they think your ferritin levels should be a lot higher than are thought over here'* [Mark, CD, FL6].

Even in treating anaemia, one of the frequently reported problems in IBD and a contributor to fatigue, there seem to be a variations in availability of intravenous iron infusion between different hospitals: *'I have talked to people who have actually had iron infusions, people who've had Crohn's and fatigue and they've bounced out the hospital, but I mentioned it to my hospital, and they're almost like, no you can't have that, absolute nightmare scenario. For somebody with Crohn's the iron tablets can be a bit harsh anyway, it will go straight through you, but they refuse to give it to me intravenously ... so I'm on iron tablets and eventually the hospital agreed that I could have a course of B12 injections'* [Mark, CD, FL6].

8.8.7 Alternative therapies

Among the range of alternative therapies used to manage fatigue were acupuncture, yoga and homeopathy: *'The biggest thing that actually helped me when I had the nine months off when I was completely drained [of energy] was acupuncture. That really got me back on my feet'* [Mark, CD, FL6]. Others tried yoga: *'I had a go at doing yoga and I think the*

relaxation side of that, I found that helpful, it doesn't cure it [fatigue] by any stretch, but I did think it helped, not massively but I think it did' [Harry, CD, FL7].

Homeopathy seemed to have short term effectiveness: *'I tried different remedies, homeopathic remedies in an attempt to try and combat some of the symptoms, not just the fatigue, and sometimes they work for short periods and sometimes they're not, it's a bit hit and miss'* [Alan, UC, FL10]. While others felt that alternative therapies were largely ineffective: *'Over the years I have tried loads of different, you know alternative therapies, but they don't work, not really'* [Gary, CD, FL8]. The frequency and duration of each session and the time over which each participant tried different therapy methods was not clear.

8.9 Psychological methods to manage fatigue

Psychological methods, such as stress management, motivation, positive attitudes and counselling were mentioned as beneficial to manage fatigue.

8.9.1 Stress management

Participants recognised that stress negatively impacts on their fatigue (see section 8.3.1) and tried to manage this: *'To deal with the stress levels, which cause the colitis in the first place, which then leads to the fatigue you know. So that's how I kind of see it'* [William, UC, FL4]. Dealing with negative emotions was also seen as helpful: *'If you're angry or something and literally just get rid of anger in two minutes then it's less stressful and therefore less fatiguing'* [Julie, UC, FL9]. Avoiding negative or stressful situations was mentioned as helpful in making things more manageable and therefore less fatiguing.

8.9.2 Motivation and positive attitude

Some participants thought positive thinking and a positive attitude to life were good strategies in dealing with fatigue: *'Just think about nice things you know, happy things, that's another good one [strategy]'* [Sophie, CD, FL6]. Even those with generally negative outlook on life tried to be more positive: *'I'm not a positive person at all, I'm a half glass empty person you know, I've never been positive. But I do, do try to say to myself when it [fatigue] happens, I'm not going to feel like this tomorrow'* [Sue, CD, FL9].

Being positive about fatigue was not easy: *'How can I be positive about the fatigue and how it affects me, I can't think what you can be positive about'* [Alan, UC, FL10]. To maintain a positive attitude over a period of time was challenging. This was partly due to not being convinced of the effectiveness of any of the methods to manage fatigue: *'There's not much I take for it [fatigue]. ... I could go and see my GP and get some, they'd probably prescribe some pick-me-up or something like that. I could probably start going to bed a little bit earlier, that sort of stuff, but I suppose in a way, it's because I don't expect that those things in themselves are going to make a hell of a lot of difference'* [William, UC, FL4].

Having a negative attitude prevented some participants from even trying different methods: *'I went to have a look at the sports centre you know, but it wouldn't have helped, because I've got UC and that was what is causing this [fatigue], so it certainly wouldn't have helped me anyway. So I didn't even try it [exercise], but I wouldn't have enjoyed it because, well I know I wouldn't have enjoyed it, but as I say, it was pointless because that wasn't what was needed, what was needed was a treatment for UC'* [Andrew, UC, FL6]. Motivation played an important part in either reinforcing participants' positive attitude or preventing them from participating in activities that could help them to manage fatigue.

Some talked about unsuccessful attempts to deal with fatigue: *'No matter how much personal care I do to myself, how I dress, what I do to my hair, what I do to my face, it doesn't make any difference to how I feel, because some people say "oh go and put a bit of makeup on you'll feel better", or "go and have your hair done, you'll feel better". Doesn't have an impact on you because you're constantly from head to toe your body's completely drained all the time'* [Sally, CD, FL8].

Some participants tried to talk themselves out of fatigue but the effectiveness of the method varied: *'If I'm just feeling a bit tired and think I might get more tired, then it's more likely to work, because instead of thinking, oh I better just sit about because I'm feeling tired and it's going to get worse, I think oh, I'm not feeling too bad, maybe if I do this, I'll perk up and I'll feel a bit better, I'll have a bit more energy ...but if it is really bad to the point where my eyes are dropping, my eyes are stinging, my body feels two tonnes of weight, then, it's almost impossible to talk myself at that point, because I've resigned myself to being too tired that day'* [Vicky, CD, FL8].

Many participants were optimistic about finding new ways of managing fatigue in the future: *'I would like to think there must be some way, I really do, I don't know what it is. I'd like to sink a magic pill, some sort of tablet I could take that would stop me from being tired'* [Sophie, CD, FL6]. Preventing fatigue was analysed in the short and the long term: *'To me, they're two different questions. Is it possible? For me, I don't believe there's anything I at this moment in time could consciously do to prevent one or more of my fatigue symptoms - no. Is it possible at some point that it will be preventable, then I think the answer has to be yes, because I think I'm firmly of the belief that the sort of fatigue I suffer from, I can't speak for fatigue in general because I don't know enough about it, but I'm confident that the fatigue I suffer from is caused by some sort of imbalance of chemicals in my body. Now my belief is that at some point we will be intelligent enough to be able to analyse what that imbalance is'* [Mark, CD, FL6].

8.9.3 Counselling

Counselling as a method of managing fatigue has been used with varying outcomes: *'I've had some counselling support and I've done quite a lot of talking therapy. But I don't feel there's anyone out there who can help me anymore, there's no one else that can make things better. I've just got to deal with it. I just feel like I'm on my own with it, because I've got to get on with it'* [Harry, CD, FL7]. Gary's journey through counselling was more positive, despite initial difficulties in engaging with counselling: *'When I went to counselling one time, I had lots of discussions about the guilt, it's like, feeling like you've got to work really hard to deserve any enjoyment in life you know. So it was a convenient excuse not to think about myself, which was one of those contradictory things, it's like I didn't think I was thinking about myself, just got on and did things, but actually I behaved in that way because I was thinking about myself, I didn't want to deal with it, so it was easier to wear myself out and do things. ... You know, the first time I went to counselling and actually got any benefit from doing it, I just sat and cried and cried and cried loads of time, and not in a distraught way but relief that I was finally able to deal with certain things'* [Gary, CD, FL8].

It seems that different individuals need to deal with their specific aspects of life in different ways. Some people may not be ready to face certain aspects of their condition and therefore may not benefit from counselling at the time when it is offered.

8.10 Behavioural methods to manage fatigue

Amongst behavioural methods cognitive behavioural therapy, change of activities, perception of being in control and prioritising were discussed.

8.10.1 Cognitive behavioural therapy

One participant talked about using cognitive behavioural therapy (CBT) to help him manage fatigue; however he did not endorse CBT as an effective method: *'What seems to be fashionable [is] CBT. I've dealt with CBT therapy and I can't for the life of me see how keeping a diary, and how responding differently to my fatigue is going to stop the episodes of fatigue. I don't want the fatigue but it's no good saying well, it's the way you're thinking that's making things worse'* [Alan, UC, FL10].

8.10.2 Change of activities

A change of activities from physical to mental, or vice versa, was at times effective in managing fatigue: *'Quite often first thing in the morning, I'll do things like filing that don't really take a lot of concentration, so that I know that when my brain's in gear I'll be able to get out there and do what I need to do, the more complex parts of the work. But even so, it doesn't always work'* [Sophie, CD, FL6]. Various strategies were used to deal with loss of concentration, but not all of them were successful or well received by others e.g. work colleagues: *'I would find that I would become quite disruptive of other people because I was finding it difficult to concentrate and get on with my work, I would be making jokes or on the internet or we'd be talking. ... I've been told several times how disruptive my influence was on other people'* [Hugh, CD, FL8].

8.10.3 Perception of being in control

Participants perceived being in control was an important part of managing fatigue and IBD: *'I feel like it's, if I was to give in I'd feel like the illness has beaten me, not just with the fatigue but the whole colitis, and I don't want it to beat me, so I want to feel like I'm in control of it, rather than it being in control of me, so I don't want to give in and let it have that control over me'* [Laura, UC, FL6]. Being in control took many different forms, depending on individuals' approaches. Some would try to *'push through'* their tiredness and not *'give in'*, not be *'beaten'* by fatigue, and try to continue with their task at the time. For others being in control would be to consciously take a break and sit down, or lie down

and have a rest: *'If it's something I can control then I feel better about it, but if I can't control it, then it does seem to make me more stressed which makes me more fatigued. ... More recently I've been trying to do yoga, on the Wii fit because it's something I can do in my own home, so if I feel ill I can sit down, or if I feel tired I can just stop, there's no pressure to continue'* [Vicky, CD, FL8].

Many of the participants agreed that fatigue *'probably'* can neither be prevented nor controlled: *'Not that I can put my finger on [how to prevent fatigue]. I've tried to think about times when I've been less fatigued and there's nothing really that does help'* [Vicky, CD, FL8]. Some had a fatalistic approach and felt powerless in preventing fatigue: *'Well I don't think you can prevent it can you, I couldn't even think of a way to prevent it. If it's going to happen, it's going to happen'* [Catherine, UC, FL6].

Some reported positive outcomes in terms of managing fatigue by being proactive: *'I've been doing these little exercises. It sounds daft but it is working, and I'd recommend anyone else who is really tired, you know really – and it gives you an achievement as well, something that you've achieved rather than just sat down or lying in bed, you've actually done something haven't you? And that's the key to everything'* [Roger, CD, FL5].

The feeling of being able to choose what they would want to do, provided the participants with a sense of satisfaction and this in turn, gave them the feeling of control. Gaining control helped to reduce the level of fatigue, however it did not mean eliminating fatigue altogether.

8.10.4 Prioritising

Many participants considered prioritising to be one of the most effective ways of managing fatigue. For those who were employed, their priority was to have sufficient energy to get on with work: *'I didn't do a lot apart from get up in the morning, go to work, come back and that was it, go to sleep, eat and sleep'* [Henry, UC, FL8]. Some worked full time but had to reduce their hours: *'I cut down my hours initially to four days a week, that was probably about 2006, so I was doing four days a week. In time that started to become difficult as well, and then I cut down to three days a week eventually'* [Hugh, CD, FL8]. Laura explained how her priorities changed over time: *'To be able to manage to go back to work I've had to look at how I spend my time and other activities that I do and try and make sure that I am spreading it out over a week and not doing too much all in one go, because otherwise I wouldn't be able to carry on with work ... [but] with going back to work, I've*

realised that I'm putting more effort into sustaining my work life, that my personal life was getting affected, so that's why we're now reducing my hours to try and get a bit more of a balance' [Laura, UC, FL6].

Prioritising was seen as helpful: *'I make real big decisions about what I'm going to do and what I'm not going to do ... well I can't, I can't do it all now I have to make, I have to work out which is more important for me, and then do what's most important, and if I do want to do things, try and space them'* [Ruby, CD, FL7]. Prioritising successfully was a skill that developed over time: *'I've got better at prioritising things that really have to be done, well the house is a mess now, but sometimes it's like, there's piles of washing that need to be ironed and stuff like that and I just leave the house in a mess because I know that I'm not up to doing it, whereas before it would be like, oh I've got to do this'* [Gary, CD, FL8].

Many participants need to prioritise their activities as they have insufficient energy to carry on with their lives as before fatigue. However this may mean that their lives become very restricted.

8.11 Situational methods to manage fatigue

Physical and psychological support, having sufficient information to understand fatigue, and forward planning were all mentioned as ways of managing fatigue.

8.11.1 Support systems

Participants talked extensively about different support systems and having understanding from others, such as a partner, family members, friends, colleagues or an employer, or HCPs as beneficial when dealing with fatigue. For some the support came in the form of physical help of taking more responsibility and doing more at home (e.g. shopping, cooking, cleaning) and for others it was in the form of advice, understanding and acceptance of the limitations caused by fatigue: *'My partner is very supportive and understanding, I'm very fortunate to have that and it makes me feel very fortunate that I know he can look after me'* [Vicky, CD, FL8]. Some realised that they are not able to do everything and they have learnt to ask for help: *'Whereas before I wouldn't ask for help for people to do stuff, now I tend to ask people, you can do this for me, you can do that, whereas*

before I would tend to do that myself. Such as help with the shopping, if someone's around I can ask them to do that for me if I'm feeling tired' [Louise, UC, FL5].

Being believed and understood about the severity of fatigue and its impact on the participant's life was considered helpful in managing fatigue. Support and understanding is required in many different aspects of life, such as personal (by friends and family), professional (employer and work colleagues) and the relationship with HCPs. Some talked about support from their partners: *'My husband, he's pretty good on this, I think he's starting to realise that it is just shattering when you are bad'* [Louise, UC, FL5]. Employers and colleagues could be supportive: *'Just knowing that they understand is a massive help'* [Sophie, CD, FL5], or not: *'Other people can't see it [fatigue], because it's like it's invisible to other people and that it's really frustrating because people can't see it happening at all'* [Sally, CD, FL8]. This lack of understanding and support led to greater frustration and isolation and resulted in more severe fatigue: *'I haven't really got anyone to talk to actually, if I'm honest, I tend to look after myself, with my bad days. That's what I miss I think, having a group of friends where you have one friend you talk to about one thing, and one friend you talk about another thing'* [Ruby, CD, FL7].

Several participants talked about their attempts of reporting fatigue to HCPs: gastroenterologists, general practitioners (GPs) and IBD nurse specialists, in the hope of receiving help and advice on how to manage the fatigue. Their experience of getting support varied from being advised to rest more, being told that fatigue is 'normal' part of IBD and that nothing can be done about it and they have to learn to live with it, to being told that fatigue is not one of the symptoms of IBD.

8.11.2 Information, education and self-awareness

Being aware that fatigue is part of IBD was a starting point in being able to manage it. Unfortunately many participants were not informed of this: *'I didn't know, because nobody told me'* [M10, CD, FL5], or they were misled that fatigue is only present during the flare up: *'In the past he's [gastroenterologist] said, you should only feel fatigue if your Crohn's is active, and I've done so much research on the internet, and that's not true, well the information I've found. Because I needed to know other people were feeling like me, because I thought well, if you're not meant to feel like this between flare ups, there's something else wrong with me then!'* [Ruby, CD, FL7].

The need for information relating to fatigue and its mechanism was frequently raised: *'I'd like to know, what my bowel is not doing, or what it is doing that's making it tell my brain that it's got to be tired. That's what answer I would love to know'* [Sue, CD, FL9]. Participants were critical of HCPs for not providing them with comprehensive information regarding fatigue: *'You want to find an answer, something to stop it [fatigue] in its tracks ... but the fatigue and what causes it, I've never been given answers to that because I don't think they know. ... If the inflammation is being dampened down, why am I still having problems with fatigue and mal-absorption, and issues like that, but nobody's explained that to me'* [Alan, UC, FL10], and participants become self-reliant and have learnt how to manage fatigue: *'You just learn day by day what suits you'* [Louise, UC, FL5].

Being self-aware was frequently used as a method to manage fatigue: *'I won't go to the doctors now, I cope with it myself because I've learnt over the last 17 years, I've learnt that I can deal with it myself, I know what to do, I know what to expect I know what my normal is, I know what my not normal is, and I have to lead my life accordingly on a day to day basis'* [Sue, CD, FL9]. Participants tried to be in tune with their body to be able to function: *'It might sound a bit odd but my priority is to try and recognise what my body's telling me so I can gauge how to deal with whatever situation comes along each day. ... I think the biggest thing really was learning how to open up a bit and deal with my emotions and my own fears'* [Gary, CD, FL8].

It appeared that finding a balance was based on individual's abilities and self-awareness: *'I know when to stop fighting and when to stop pushing ... I do what I can and recognise the limits; if I'm having a good day, get out there, get stuff done, if I'm not having such a good day, just chill and relax a little bit and just take it easy until I do feel better'* [Sophie, CD, FL6]. However, finding the right balance between the activity and rest was a challenging task: *'Certainly it took me a long time to work out where that balance was, and to accept that once I started feeling in a certain way, I had to stop what I was doing, otherwise I'd regret it tomorrow, does that make sense?'* [Mark, CD, FL6]. Another challenge was finding a balance between physical and mental functioning: *'You soon get to know how your body works, the physical side of it anyway, not quite perhaps so much the psychological side, so with that side it's relatively easy, but obviously with the fatigue side where it's all about, as far as I can see, it's all about minute changes in chemical balances in the brains and in the body, that's much more difficult'* [Mark, CD, FL6].

Participants talked about holistic approach as a way forward to fatigue management: *'There must be some way that you can holistically try and pull it together, although I understand all the things, it's individual, and nobody knows what it is that's doing it for one person or another person, but that to me just says it's more difficult to work out what to do [and] it would be interesting to know what's causing it, but what I really care about is how to deal with it'* [Julie, UC, FL9].

Some participants advocated educating and raising awareness of fatigue among the general public and HCPs: *'Assuming my situation's fairly normal for someone with Crohn's, I would love if people could have acknowledged that what I was experiencing was normal ... I think I'd like to see education of healthcare professionals and the public, that this is normal for someone with Crohn's, or it can be, because I know not everyone with Crohn's is like this'* [Harry, CD, FL7].

8.11.3 Forward planning

A few participants used advanced planning to manage fatigue: *'If you have plans for the day, you can find the energy and get on with things. I find if my days are full I cope better, I can be more motivated. I mean I'm still fatigued, I still feel really, really tired and worn out and exhausted'* [Sally, CD, FL8]. Setting achievable targets created positive feelings: *'I'll set myself a plan for the day and it'll always be a very low plan because in order to stay happy, I like to set myself a goal I know I can exceed every day so I feel positive about it rather than feeling oh I've never achieved anything'* [Julie, UC, FL9].

Some, who did not work or were self-employed, tried to rest more towards the end of the week [Thursday, Friday] to make sure that they had energy at the weekend, to spend time with their partners and family: *'I don't want to be in bed, I just am not going to go to bed because it's the weekend and I'm not going to waste the weekend being in bed'* [Julie, UC, FL9]. It would appear that for some participants forward planning helps them to manage their energy to deal with fatigue.

8.12 Combination of methods to manage fatigue

Participants talked about a variety of methods to manage fatigue that they had tried, for shorter or longer periods of time, with varied outcomes. Often they tried a mixture of

different methods simultaneously: *'I'll go out and get some fresh air, for example, or if I see a friend I'll feel bit more perked up'* [Vicky, CD, FL8]. Use of a combination of different methods did not always provide the desired and long lasting effects: *'Sometimes I've gone and stood outside and got some fresh air, change of atmosphere, put music on, put it on louder than what I would normally to try and keep myself stimulated, but nothing seems to work, it only works temporarily, no more than an hour, it doesn't stop it [fatigue]'* [Sally, CD, FL8].

Finding the right balance between different methods was challenging: *'I think it seems to be a case of getting the balance right, the right amount of sleep, the right amount of sort of physical or mental stimulation and trying not to worry about things is the way of getting through it'* [Hugh, CD, FL8]. There were strong advocates for stress management and relaxation as a way of keeping fatigue under control: *'Things like trying to relax, you know, if you feel a little bit stressed out, because that does have a knock-on effect at some point, it's like, have a nice warm bath, relax, read, get away from the stress, even if it's for an hour to let your mind unwind and that helps your energy levels'* [Louise, UC, FL5].

None of the participants were fully convinced about the effectiveness of different methods in fatigue management: *'I've tried to exercise to try and think, well if I exercise more, then I will be fitter so I will feel less fatigued, but I'm too fatigued to exercise, and exercise exacerbates my Crohn's symptoms'* [Vicky, CD, FL8].

8.13 Summary

This chapter presented many different factors contributing to fatigue. The range and combination of factors differed between participants. The presented factors had a direct or indirect influence on fatigue and the relationship between factors was depicted as complex and varying. Most of the factors contributed to fatigue severity. The range of factors and the order in which they appear needs to be assessed for each individual person, if effective management strategies are to be employed.

While participants tried different fatigue management methods, most were not effective or only had a short term effect in reducing but not fully alleviating fatigue. Only a few of the methods (low grade exercise and relaxation) were presented as sometimes having a positive and a longer lasting effect on fatigue and its severity. Most management methods were tried

for only a short period of time, or were tried in an unsystematic way. The level of motivation and the participant's positive frame of mind seems to play an important role as either an enabler or a barrier for how the participants benefit from the management methods that they use. This needs to be further investigated if the negative impact of fatigue on people's lives is to be reduced. The impact of fatigue is discussed in the next chapter.

Chapter 9 Perceived impact of fatigue on individuals' lives

9.1 Introduction

Against the background of the many different characteristics of fatigue (Chapter 7), factors contributing to fatigue and mostly unsuccessful methods of managing fatigue (Chapter 8), this final results chapter provides the composite textural and structural description of the impact of fatigue. The chapter covers the remaining two themes and aims to:

- Present the impact of fatigue on different aspects of people's lives, and
- Present the combined effect of fatigue and illuminate the experience of living with fatigue.

Fatigue was perceived to have negative and damaging effects on physical, psychological, cognitive and social functioning (Table 9-1). The impact was often described by what participants could no longer do, rather than by what they could still do. Structural analysis revealed that fatigue affected people in three different ways: by limiting, stopping or changing their activities or moods across different aspects of their lives.

Table 9-1 Impact of fatigue on individuals' lives

Aspects of life	Extent of impact (structural)	Area of Impact (textural)
Physical	Limits me Stops me Changes me	Everyday personal functioning Daily household activities Education and employment
Psychological/ Emotional	Limits me Stops me Changes me	Mood, anxiety and depression Motivation and frustration Feeling of freedom Confidence, self-esteem and self-image
Cognitive	Limits me Stops me Changes me	Concentration Memory Thinking process and creativity
Social	Limits me Stops me Changes me	Hobbies and interests Socialising and going out Holiday and travelling Personal relationships and significant others

Fatigue ‘limits me’ relates to the restricted speed and range of participants’ daily activities and roles; fatigue ‘stops me’ relates to activities and roles that participants are no longer able to pursue or fulfil; and fatigue ‘changes me’ relates to activities (e.g. sleeping during the day) or emotions (e.g. anger, frustration) that participants would probably not experience to such a large extent if they were not fatigued.

9.2 Perceived impact of fatigue on physical functioning

Fatigue impacted on everyday functioning and activities such as looking after oneself, family and children, household chores, work and employment.

9.2.1 Physical everyday personal functioning

Daily personal physical functioning was affected by fatigue. Participants talked about its limiting impact on everyday activities such as washing and dressing, walking, sleeping and exercise, amongst others. For some, severe fatigue created considerable difficulty leading to reliance on help from other people: *‘I feel like it’s something that would happen to someone older, not being able to wash and dress myself. ... I was just so exhausted, I couldn’t stand up in the shower’* [Laura, UC, FL6]. Severe fatigue reduced participants’ ability to undertake basic activities such as walking even short distances: *‘The marathon runners talk about a brick wall, well that’s exactly what happens to me. I just hit this brick wall and I just, I can virtually not move’* [Andrew, UC, FL6]. IBD symptoms and not having energy further prevented some participants from physical activity: *‘I’m too fatigued to exercise, and exercise exacerbates my Crohn’s symptoms ... I don’t even want to go for a walk because I’m just too tired’* [Vicky, CD, FL8]. The enforced sedentary style of life resulted in some participants becoming housebound: *‘I might not go out of the house for days because I’m so weak and tired’* [Harry, CD, FL7].

Fatigue forced some to sleep during the day, consequently affecting their night-time sleep: *‘I’m sleeping a lot during the day because of the fatigue, so I don’t really sleep, I go to bed at night, [but] I’m up and down all night’* [Alan, UC, FL10]. Since the onset of fatigue, sleep did not have the same refreshing effect: *‘Before I developed the fatigue, [I] was waking up and feeling really refreshed and I’d had a good night’s sleep, I don’t get that any more, most of the time I feel like I’ve woken up and someone has just drained me of all my energy’* [Sally, CD, FL8].

A few participants mentioned frequent headaches and pain related to fatigue, however the direction of the relationship between these two was not always clear: *'I'm not sure which way it is, whether it's because I'm so tired I feel a lot of pain or whether it's because I'm feeling more pain, that I'm so tired but somehow they're linked'* [Fiona, CD, FL 7]. It is possible that the relationship is two-way: *'I think it can work both ways can't it, very often the pain that I get in my shoulders and my back and my neck and the headaches that I get, those kind of aches and pains come from the fatigue'* [Gary, CD, FL8].

9.2.2 Physical daily household activities

Everyday activities such as shopping, running a household or looking after the family were considerably affected by fatigue: *'When the tiredness descends on me it's really very, very difficult to do any jobs'* [Sue, CD, FL9]. Fatigue slowed participants down in carrying out their daily activities: *'I can't clean the house in one go, I just don't have the energy and you just want to sit down and just take a rest in-between'* [Louise, UC, FL5]. Being unable to do everyday activities left participants feeling incompetent: *'I tend not to do that much housework any more, which isn't me because I'm very house proud.'* [Sally, CD, FL8].

Physical activities took much longer to complete because of fatigue: *'Then energy-wise, like the front lawn there [pointing to the front garden], it used to take me about seven minutes to cut that – I cut it ten days ago, and it took me just under an hour - 55 minutes'* [Andrew, UC, FL6]. Inability to do physical activities affected their self-perception, made them feel weak with no energy. Participants were aware that other people could stereotype them and label them as *'lazy'* and *'not being bothered'*. Slowness or inability to undertake or complete day-to-day activities led to participants being frustrated and this was compounded by perceptions of other people's negative judgement.

Some participants' perseverance with day-to-day activities may lead to putting themselves or others at risk: *'I've driven so many times when I've had that awful tiredness and ... I don't even remember going down the road it's been that dangerous'* [Sue, CD, FL9]. Not being able to drive restricted some participants' social and professional opportunities, resulting in reduced involvement in family and social activities: *'I can't drive long distances so I can't visit my parents any more. They live a long way away'* [Vicky, CD, FL8]; as well as professional activities: *'I am looking at progressing within the company to doing a different job, and depending on which job I do, one of them could involve more*

driving, and I'm just hoping that by that time, I won't feel so fatigued all the time' [Sophie, CD, FL6].

9.2.3 Education and employment

Many people are diagnosed with IBD early in life and fatigue affected participants' ability to study, impacting on their education and subsequent work lives. Poor attendance at school or university, low concentration and not having enough energy reduced their academic achievement at school: *'I didn't get the chance to finish all my GCSEs, even though I'd started and done a lot of the coursework. ... I ended up being tutored at home, as I was so tired and weak'* [Fiona, CD, FL7], and at university or college: *'I was going to do a degree ... I did try, about 2 years ago I went and did a college course, but I just couldn't do it, I just haven't got the energy'* [Ruby, CD, FL7]. Some managed to finish college education as part-time mature students while also working: *'Tiredness and fatigue was always there, [but] I did cut my [work] hours and I did my A-level course in the evening, which eventually led me on to go to university when I was twenty-five'* [Hugh, CD, FL8].

A few of the participants questioned their own capabilities of learning new skills: *'Whereas before I never questioned myself I just got on with it, this time I'm actually questioning my ability to do it [complete a professional course]'* [Sally, CD, FL8]. Some participants believed that others saw them as not trying hard enough: *'My dad called me lazy, but I always had stomach problems and I was exhausted'* [Catherine, UC, FL6]. For many participants, fatigue meant not being able to study for qualifications that would have allowed them to work in their chosen career: *'The PGCE course I was doing was only a year, and it got to the point where, I still loved the idea of working with kids, I had my own little desk in my bedroom, I had everything sorted out, work plans, materials to use working in classes and stuff, and I remember just sitting there staring at it, because I just hadn't got the energy to do anything'* [Gary, CD, FL8]. Participants often had to choose between work, study or being exhausted, as they did not have enough energy for everything. This trade-off left them feeling that they repeatedly lost out, and were never winners, having to settle for second best. This sometimes led to feelings of sadness and regret: *'I'd love to experience going to college'* [Fiona, CD, FL7].

Fatigue had a considerable impact on employment. Participants talked about their struggle to get through each day at work: *'I'm holding myself together, trying to get through work because I feel really tired and I feel really uncomfortable'* [Gary, CD, FL8]. They did not

have energy to fight and to sustain motivation: *'I wasn't too interested in it [work] really, whether it's putting off, or putting it to another day, not taking it as seriously as I should have been, and not really caring whether I did certain bits or not. I did get behind in certain parts of it ... I did make a few mistakes, which were embarrassing'* [Henry, UC, FL8].

Some participants found coping with fatigue and a full-time job too difficult to manage and had to reduce their working hours: *'I've changed to four and then three days'* [Hugh, CD, FL8], or to retire early on health grounds: *'I asked if they would consider medically retiring me ... It really was getting too difficult with the journeys, and the stress and all that. I have worked since, but on a part-time basis, and I was lucky enough to find something ... only just up the road from me'* [William, UC, FL4].

For those who are unable to sustain the same level of employment, the loss of perceived status and professional identity was sometimes difficult to cope with: *'I see myself as being the main breadwinner, it's my job to look after my family and kids ... I did find it very, very difficult of getting used to the idea of not actually being the one that has to go out and do all this stuff and all the rest of it, and I still have difficulty with that change of roles, and a couple of years ago I was quite depressed as a result of it, I sort of felt my role was being eroded'* [William, UC, FL4].

Some tried to continue with employment, but ultimately faced defeat: *'I was having periods signed off work [because of fatigue, so] ... I decided to take a career break, I took six months off work, and I only went back part time, but I lasted about three months and then I had to give up completely'* [Mark, CD, FL6]. For some it was a gradual process of reducing their working hours before having to make the decision to give up, while others had the decision made for them: *'I'm not working at the moment ... Well they sacked me ... The fatigue and weakness has been so debilitating ... that for me [this] is the main reason why I'm not able to hold down a job ... I was at the top of my profession as well and I couldn't keep going'* [Harry, CD, FL7]. Harry felt angry and frustrated about losing his job, particularly as he felt discriminated against that his health was not taken into consideration when the employer terminated his contract.

Some participants had to change their employment to something that was less taxing and more suited to their current level of energy: *'I was lecturing at university, and it was very difficult to stand for two hours at the time, so I've decided to change [to a more office based job]'* [Vicky, CD, FL8]. Long hours were the deciding factor for others: *'I was working*

with TV companies and they were quite long days, sometimes eleven, twelve hour days, and I couldn't do it, so I had to change and now I'm in IT' [Hugh, CD, FL8]. **Having** to, rather than **wanting** to change employment left some participants with the feeling of being controlled by fatigue. Participants often perceived these changes as negative, as they were made not out of true choice but were forced upon them by fatigue, and the new jobs were of lower status and lower remuneration: *'I was always into film and video, that's what I did at university, doing something more creative with my life ... I'm kind of stagnating now'* [Hugh, CD, FL8]. Not being able to realise their full potential was viewed by participants as lost opportunities, making them feel that fatigue is controlling and severely restricting their lives.

Being overtly tired at work creates challenging situations for participants: *'I just wanted to go to sleep right there and then, but of course I couldn't when I was at work so it was very uncomfortable, especially as my manager was only about 10 feet away from me, so it was very embarrassing trying to hide behind the computer'* [Henry, UC, FL8]. Their professional image and credibility was at stake as a result of fatigue: *'My work involves lots of meetings and, just suddenly, losing it, just forgetting what I'm talking about, mixing up words... [but] I don't want them [colleagues] to think that I'm stupid'* [Gary, CD, FL8]. Interactions with colleagues at work may be problematic: *'When I'm very tired, I'm not very responsive, it's just the way somebody asks you a question or tells you something, I obviously give quite curt, abrupt responses to people, and sometimes I'm not aware that I do it'* [Gary, CD, FL8].

Concentration difficulties resulted in participants making mistakes at work: *'I do remember one day I put in a Lira amount as a Sterling amount, and it was something like 10 million, it was a silly, you know, Lira to the Pound is millions, or thousands. ... My manager came in and he was to authorise it, and he said, what are you doing? This is Pounds and it's supposed to be Lira, and I was like 'Oh!' It was little mistakes that could have been huge; silly little mistakes like that'* [Catherine, UC, FL6]. Making mistakes when fatigued made participants feel embarrassed and lose their self-belief in being able to do the job. Some protected their image as a good employee, by trivialising the mistakes: *'I'll make little mistakes in my work, and I'm finding, 'Oh well!' - whereas usually I'd have been - 'Oh God!' You know, it would have been annoying but I just haven't got the energy to be annoyed about it'* [Sophie, CD, FL6]. It is difficult to determine if this is an example of a *'don't care'* attitude created by constant fatigue and having a limited pool of energy, or a strategy for self-protection and image management. Catherine's experience (presented

above) supports the latter point, as she is still affected by her experience even years later: *'When I was working I remember one day I fell asleep on the phone! There was a man talking to me on the phone and I fell asleep on the phone, now it's something that always stuck in my mind'* [Catherine, UC, FL6].

The impact of fatigue threatened participants' credibility as professional and reliable employees. Participants tried to conceal their level of fatigue as they were worried about the consequences: *'If they [employer] knew how tired I am they wouldn't put me forward for training and I would be overlooked for promotion'* [Vicky, CD, FL8]. Being fatigued restricted or stopped some participants' chances of being promoted: *'I think my absences have definitely had an impact on that [being promoted], and they [employer] have admitted that themselves'* [Hugh, CD, FL8]. Some restrictions were self-generated: *'I hold myself back I think, because I'm scared to take anything new on because of how the fatigue will affect that'* [Hugh, CD, FL8]. Participants also felt that taking on extra or higher level of responsibilities may have negative impact on their health.

Reduced working hours, being overlooked for promotion or not being in employment because of fatigue meant that some participants experienced financial hardship: *'We've not got the income that we had, so financially, financially the impact has been massive so that's a big issue'* [Harry, CD, FL7]. Some had to return to work from sick leave before fully recovering: *'If I didn't go back to work when I did, I was running the risk of having my pay cut to half pay and I didn't want to run that risk for financial reasons'* [Laura, UC, FL6].

9.3 Perceived impact of fatigue on psychological functioning

Fatigue impacted on participants' psychological wellbeing and psychological functioning. This resulted in low or depressive mood, negative feelings, difficulties in connecting with others and reduced quality of life.

9.3.1 Mood, anxiety and depression

Fatigue and inability to function 'normally' affected participants' mood: *'On a horrible day when my tiredness is unbearable and heavy and horrible, I don't know where I am to start with, and I look ahead and I know that all the things that I should do, and know I'm not going to do them so I automatically make myself miserable because I'm thinking 'Oh*

no! I'm not going to be able to do those today'. ... This heavy tiredness, it drags you down, it drags me, it really drags me down ... it's horrendous just to think about it' [Sue, CD, FL9].

Some participants were not aware that fatigue could be part of IBD and were psychologically unprepared for it and its consequences: *'I sunk into depression because of it all. ... Having the Crohn's, having the operation and then developing the fatigue, nobody warned me that that could happen'* [Sally, CD, FL8]. The gradual debilitating effect of fatigue affected their psychological well-being: *'I think that fatigue has an extra strain on the kind of mental health side of things, because it just wears you down eventually'* [Hugh, CD, FL8].

The unpredictable nature of fatigue affected participants' emotional state: *'I started getting anxiety attacks, and panic attacks but it became very clear that it was related to my health, it had become a vicious cycle. I'd have something booked to do in a week's time, and I'd get so worked up about whether I'd be well enough, have energy to do it, that I'd be too ill to do it, does that make sense? And that became a real problem, and that in tandem with the fatigue, and I could then never work out what was anxiety and what was the fatigue'* [Mark, CD, FL6]. The boundaries of fatigue blurred as if infused with other feelings such as anxiety or depression, making it difficult to unravel which was cause and which was outcome.

Those participants who were clinically depressed experienced even more pronounced negative feelings. Alan, who had severe fatigue and who was depressed, questioned the sense of his life: *'Fatigue gets me down, because at the moment, the way things are, every single day. ... I am angry, frustrated, depressed, part of you feels you're backed into a corner. ... What's the point of me getting up sometimes, what's the point of me waking up, it'd be better if I died in my sleep because at the moment my life is just one monotonous, get up, have a bit to eat, fall asleep like some 90 year old geriatric. And what is the point in that?'* [Alan, UC, FL10]. At the age of 54, Alan felt old and resigned to wearisome existence. Fatigue pushed him into a corner with no visible exit and no strength to get out and live an active interesting life. The debilitating effect of fatigue made him feel much older than his chronological age and gave him no sense of purpose. He wished for a peaceful death rather than having this pointless dreary life of being fatigued. Gary, who had been depressed in the past, recalls his feelings in relation to how he is now: *'I'm low in mood, I'm not depressed now. I used to be depressed in the past, so I know the difference.*

.... No I don't feel like that now, but I have felt like that over the years, I've felt like that lots of times. ... I just thought well I can't be bothered. If I go to bed and I fall asleep and I don't wake up, I don't care' [Gary, CD, FL8].

For many there was a progressive trajectory from fatigue to depression, or depression leading to more severe fatigue, but for some there appears to be a parallel co-existence between fatigue and depression with constant intertwining between the two. Some participants were trying to explain the complex relationship between depression, fatigue and other factors: *'The depression I think comes from not being able to be in control of your life. I think depression is just a feeling of uselessness and inability to cope'* [Catherine, UC, FL6]. Being out of control of their life made participants unable to steer and keep their lives on course to achieve their aims and plans. Fatigue took over, and felt they were just passive observers of life being like a drifting boat, being thrown by waves of fatigue in different directions without a sense of purpose.

9.3.2 Feelings of low or loss of motivation and frustration

Motivation, frustration and fatigue seemed to be closely related and impacted on one another. Every participant talked about fatigue-related frustration: *'Unfortunately you will hear from me a lot of frustration, which is probably what you hear from a lot of people, because I suspect that I'm not the only one in a similar situation'* [Mark, CD, FL6]. Fatigue had a negative impact on motivation leaving participants frustrated and with a *'can't be bothered'* attitude: *'I'm absolutely miserable. I've just got no incentive in my own mind. ... I sit in my scruffs and it's such an effort to even to change my trousers and my jumper you know, to get myself to go out'* [Andrew, UC, FL6]. Participants who were affected by low mood also struggled to see a purpose in life: *'A balance tipped with the mental side of things and I started to think, well what's the point of doing anything ... I'm struggling to motivate myself to do stuff'* [Hugh, CD, FL8]. Participants talked about losing their motivation to be active: *'The incentive to get up and go and do things, I lost that as well through the fatigue, it's like oh I just can't be bothered, I'm just too tired, but I know I should be getting up and doing stuff'* [Sally, CD, FL8].

Participants felt annoyed and frustrated that their *'life is passing and [they could not] enjoy it as much as [they] should'* [Henry, UC, FL8]. Their 'new life' with fatigue is more about existence and surviving from one day to another, and not living their lives as they would like to.

9.3.3 Feeling of loss of freedom and lack of control

Participants felt they had lost both their freedom and their sense of control because of fatigue leading to a sense of imprisonment in their own body and in their home. Lack of energy restricted what they could do: *'When I'm fatigued, basically I don't go out the house much at all, because I don't have the energy, and this room that we're in now is where I spend most of the time'* [Harry, CD, FL8]. Fatigue influenced how far participants could venture: *'Because of the colitis and the tiredness I didn't feel like going out too far or going anywhere really. So I think you're a bit more stuck at home than you would be normally, so that would be nice, just to get a little bit more freedom outside'* [Louise, UC, FL5]. They had no freedom of choice and felt they could not be spontaneous: *'I can't just get in the car and go anywhere whenever I wanted'* [Sally, CD, FL8].

9.3.4 Confidence and self-image

Fatigue made participants re-evaluate their self-image, particularly when they could not get on with their life: *'I felt a failure ... it's still hard because I'm out of my comfort zone ... I've got my comfort zone, my everyday life, when I'm out of that it is scary'* [Sue, CD, FL 9]. Participants were unable to engage in activities, resulting in them feeling useless and having negative self-image: *'You can't do anything because you're tired all the time. Feels pretty hopeless really, you're bloody useless'* [Roger, CD, FL5]. Catherine's confidence was affected by forgetfulness: *'I've got bad memory, I can't take stuff in, it doesn't stay in my mind. So it kind of affects your confidence a lot, you know, your self-esteem, you think, I just can't get to grips with this at all. ... It's terrible, it's embarrassing'* [Catherine, UC, FL6].

Fatigue and related forgetfulness could lead to functional errors: *'I don't like to make mistakes anyway and I always think that I can check everything... and it affected me and I saw that there were more mistakes happening more often'* [Henry, UC, FL8]. Confidence was also linked with the mental effects of fatigue: *'I think confidence particularly this year has taken quite a tumble, because with the work and the depression side of things'* [Hugh, CD, FL8]. Low confidence had negative impact on work and social situations: *'It's embarrassing, because if we're in company and I start to say something and then I doubt myself when I'm saying it, like I'm doing with you just now, and I doubt myself, I think – did that happen?'* [Catherine, UC, FL6].

It was important for participants to protect and maintain their positive self-image: *'It's alright to say you're talking like an idiot today, that kind of thing. Because actually I feel sometimes that's what I do, it's like I talk and witter on and then feel like I've not really said anything, or not really got over what I want to say ... you know, there is an element that's really upsetting, because I don't want people to think that I'm an idiot'* [Gary, CD, FL8]. Image management was important for participants and they tried to avoid being labelled with derogatory terms and characteristics, that implied that they are e.g. stupid or lazy.

9.4 Perceived impact on cognitive functioning

Participants' concentration, memory and thinking processes were all affected by fatigue.

9.4.1 Concentration and concentration difficulties

Fatigue led to concentration problems: *'My head feels very like cotton woolly, very like fuzzy ... I get very dozy ... I think my head is probably the worst bit that gets affected, because like your mind, and not paying attention to people, and people get annoyed with you ... 'What? Weren't you listening?', 'No not really, I was dozing off''* [Fiona CD, FL7]. *'Day dreaming'* and being *'spaced out'* affected participants' ability to focus: *'Concentration would suffer, you would lose interest – I could be at a meeting or any kind of informal gathering at work, within two or three minutes I'd just shut off completely'* [Hugh, CD, FL8]. Reduced concentration had the characteristics of body and mind disengagement. On these occasions, the body was present, but the mind was missing.

Some were not able to deal with more complex activities: *'If I've got to do more than one thing I get flustered, it's hard to concentrate, I'm better if I can just do one thing'* [Ruby, CD, FL7]. More complex activities often gave way to less challenging pursuits such as watching television. Although, sometimes even that was too cognitively demanding in terms of following the story lines: *'I can't sort of concentrate on anything, even the television, reading a magazine and I get very irritable'* [Sue, CD, FL9].

There is a chain of events starting from fatigue that leads to reduced concentration and an inability to function. Making people feel irritable is a clear example of how the different dimensions interrelate with one another.

9.4.2 Memory

Fatigue affected the memory for all participants: *'I just don't have the mental acuity and sharpness that I used to have, but this coincides with – the more tired I am, and the more fatigued I am, the more brain fog I have. I just can't think quickly, clearly, I can't think sharply'* [Harry, CD, FL7]. Some participants became increasingly forgetful: *'I forget things so much more easy now ... people have always said to me 'How do you remember that?' - because of the work I've always done ... you have to have that good recall memory, that has been impaired through the fatigue'* [Sally, CD, FL8].

Diminished information recall contributed to some participants' negative self-image and questioning their intelligence: *'I would think, 'Oh how could I be so stupid', you know, and the memory side of things, possibly that was caused by the tiredness. ... People would sit and explain things to me for a long time, but I wasn't managing to take it all in. ... To be honest with you, I just thought it was just me, and I just thought 'Oh it's me I've got a bad memory, I can't take stuff in, it doesn't stay in my mind''* [Catherine, UC, FL6].

Excuses for impaired memory were made by some participants: *'My memory's really, really shocking, they used to laugh at me because my memory's so bad, but ... well I just thought it was just my age'* [Catherine, UC, FL6]. Catherine was 49 years of age at the time of the interview, and as she (until this study) did not know that fatigue could be a symptom of IBD, she had not considered her poor memory to be related to IBD.

Memory problems often caused inconvenience e.g. forgetting people's names, or dates of meetings, whilst others potentially had a more detrimental effect: *'[Child's name] is not well now, and I don't remember to give her medicine. I have to write it down or I'll forget'* [Catherine, UC, FL6].

For one participant memory and concentration problems led to panic attacks: *'Originally when I was really bad, the number of occasions where I've just walked out of supermarkets, just left the trolley, and you just have to go out and sit in the car and just breathe and you know, you just can't go on wherever you are'* [Mark, CD, FL6].

9.4.3 Thinking process

Mental acuity was adversely affected by fatigue: *'All my life I've been a great thinker it's what I did really, I just sat at a desk and thought, and now because I'm so tired, I can't*

think of anything to say, my mind goes blank, it's weird, it's horrible, I've always had a very quick brain, you know, instant decisions and they've got to be right' [Roger, CD, FL5].

Diminished mental acuity not only affected participants themselves but may have had a negative impact on the safety of others: *'I think it was dangerous, because I was working directly with patients most of the time, when I was tired, I couldn't think clearly and sharply as I wanted to a lot of, not all the time, but a lot of the time'* [Harry, CD, FL7]. This in turn limited life opportunities: *'Mentally, I feel if I wasn't tired so much, and I wasn't struggling, then I would perhaps be doing so much more with my life, but because it's always been there to some extent, and particularly worse the last couple of years, and it's kind of I'm stuck in a bit of a rut really'* [Hugh, CD, FL8].

Gary's speech problems were so prominent in terms of making himself understood that he sought professional help: *'I saw somebody a few years ago, she was a doctor, she was saying it is, it's a type of aphasia is it?, you know what people have when they have a stroke, just forget their words and stuff – I do that kind of thing all the time because I'm, I think a lot of the time I'm just so tired that I can't think things through very clearly, I mean it's like I'm doing it a bit now'* [Gary, CD, FL8].

9.5 Perceived impact on social functioning

Fatigue impacted on participants' social life, affecting their pastimes and other interests such as socialising, travelling, going on holiday and personal relationships.

9.5.1 Hobbies and interests

Prior to IBD diagnosis and the onset of fatigue, most participants engaged with a range of hobbies and interests, both individual and group. For all participants, fatigue meant an inability to continue with, or a reduction in their level of activity: *'I was a very physical, healthy fit person. I used to go to the gym sort of 4 to 5 times a week for a couple of hours at a time ... I used to be a professional wrestler, I used to horse ride ... that's completely out of the question now!'* [Vicky, CD, FL8].

Having to give up their activities affected participants physically and emotionally: *'The big thing is, I can't go out and play golf, which I would absolutely love to. I'd got it all planned, I was going to play until I was 90.... I used to play golf every day and I can't now. It's sad.'*

It was the biggest part of my life’ [Andrew, UC, FL6]. Group activities also provided social interaction and a sense of belonging, which fatigue took away: *‘I still love walking, but I can’t walk any more. But it was nice because you can talk all the time can’t you when you’re walking, walking is not about walking it’s about chatting, and we quite enjoy it’* [Roger, CD, FL5].

Some participants took part in competitive activities and now that they were not able to pursue their passion, they missed the excitement: *‘I was show jumping; it would always be to qualify for the next thing, or winning this competition, I always want to have something to strive for’* [Vicky, CD, FL8]. Some tried to continue with their hobby for a period of time, before they were defeated: *‘I did karate for two or three years ... but it was getting less and less easy for me, and I’d gone from going twice a week to going once a week, to once a fortnight and in the end I thought I’m not getting anywhere’* [Hugh, CD, FL8].

Hobbies and interests such as theatre and cinema, or arts and crafts were also affected: *‘I always like to try going to plays, cinema, art galleries, museum or whatever ... When I was fatigued I just didn’t even think about those things so that was a big difference’* [Henry, UC, FL8]. Participants missed not being able to do their activities: *‘I’d like to be able to get back into my art activities, my tutorial group and the village art club where we sit around, we talk, we do some art but mostly it’s talk’* [Robert, CD, FL4].

Fatigue deprived participants of an ability to pursue their hobbies and interests, and through that, they lost aspects of what defined them as individuals.

9.5.2 Socialising and going out

All participants’ social lives became limited or non-existent as a result of fatigue: *‘Fatigue destroyed my life completely ... I don’t feel part of anything anymore ... Ten years ago I had a fortieth birthday party and the hall was filled with people. ... Now I’m really isolated, I’ve only got one real close friend, all the others have gone’* [Ruby, CD, FL7]. Participants felt unable to be spontaneous and did not accept peoples’ invitations at short notice and did not instigate going out: *‘I would try to go out whenever I was asked, but I would try not to initiate any social outings’* [Henry, UC, FL8].

Not being able to socialise due to fatigue led to participants losing their previous friends and becoming socially isolated: *‘I went from being very bubbly, very energetic, to not going out because I was too exhausted. So I was cut-off socially. It was really hard, I felt very*

lonely, very isolated,’ [Fiona, CD, FL7]. Losing the old circle of friends, along with an inability to make new friends, reinforced participants’ feeling of loneliness.

There were negative consequences for participants whether they decided to socialise or not: *‘I would like to go out but I know that I’m going to feel awful either if I don’t go or if I do go, because I’ll be feeling tired because I’m there and I’m going to feel tired the next day, therefore the fatigue has beaten me because it stops me doing what I want to do.’* [Hugh, CD, FL8]. For participants, going out did not equate with pleasure and entertainment. It was perceived as hard work, requiring concentration and use of their limited energy: *‘I can come across with people as quite standoffish and quite rude, but it’s because I just haven’t got the energy to do it... I don’t want to talk to anyone because that means I have got to actually concentrate and listen, say something back, join in, and that’s an effort’* [Ruby, CD, FL7].

Going out did not mean being able to fully take part in the activities: *‘I didn’t really want to go out or see people because after a while, I would be having to fight to stay awake or, even if we’re out having a few drinks or that, 10 o’clock or whatever that would be it, you know, I’d want to go home’* [Henry, UC, FL8]. Complexity of social interaction, being in the company of others and having to concentrate for a period of time exacerbated fatigue: *‘Certainly a situation where there is a lot of people talking, and noise, well that drains my energy very quickly, because my brain seems to get overloaded, I don’t quite understand what it’s doing, and gradually the whole thing will spin’* [Mark, CD, FL6].

Limited social activity due to fatigue resulted in some participants developing social anxiety: *‘If I can find an excuse not to go somewhere, then I will. I don’t go out unless I have to. Not that I don’t want to be in people’s company, I don’t know, confidence I think’* [Catherine, UC, FL6]. Infrequent socialising also led to a decrease in participants’ social skills: *‘I forget how to talk to people’* [Ruby, CD, FL7]. This contributed to the fear of being revealed as socially inadequate: *‘I would hate it if people would invite me to a party or something like that, because I’d just be scared that I’d be so exhausted that I wouldn’t be very good company’* [Gary, CD, FL8]. To avoid the negative experiences, some participants decided to withdraw from social life altogether: *‘I have consciously put myself into a situation where I don’t do that [socialise], which I suppose could be a bad thing longer term’* [Julie, UC, FL9].

Fatigue stopped or significantly limited people's ability to socialise, resulting in isolation, loneliness, withdrawal and depression. Social interaction is an important aspect of human behaviour and wellbeing and its absence diminishes people's quality of life.

9.5.3 Holidays and travelling

Participants reported not being able to travel and holiday as much as before IBD and fatigue. Some changed their travel arrangements to accommodate reduced energy levels while others gave up taking holidays or travelling altogether: *'The thought of going on a four hour drive, I think I would have to pull off the road quite a few times now to have a few naps, or stay overnight ... I can't do it now, it's too much hassle'* [Catherine, UC, FL6].

Not being able to travel as much as before IBD and fatigue, or not being able to travel at all, deprived the participants and their families of new experiences: *'Well, that wee lass [12 year old daughter] has never been to a sunny place'* [Catherine, UC, FL6], or they were excluded from family activities: *'The last two or three years [partner's name] she's taken her Mum on holiday abroad, because I can't go'* [Mark, CD, FL6].

Participants' perception that a holiday was a time of being active, rather than a time to relax, further influenced their decision not to take part: *'I don't feel justified in saying "Let's go to somewhere for a week and by the way at least three of those days I'm going to have to do absolutely nothing". To me, that's a complete waste of money; at the end of that I need to come back have two or three days where I do virtually nothing'* [Mark, CD, FL6]. The sense of a 'glass half empty' was enough to deter some participants from taking holidays. Fatigue impacted on participants' financial situation due to unemployment, loss of job or reduced hours, limited their ability to afford to travel: *'If we go on holiday, well number one, we've not got the income that we had, so financially the impact has been massive'* [Harry, CD, FL7].

Even a day's trip was a challenge: *'I desperately would like to go to the Tate and my husband said, "Let's go down to London for the day". And I think – "I can't. I can't just go down for the day", I'll have to worry about the toilet, and I'll be so exhausted. I'd have to medicate myself up so much and, it wouldn't be worth it, I wouldn't enjoy it, I'd be irritable, snappy, I'd just, total waste of time to do it, basically, for me it's not worth the effort'* [Ruby, CD, FL7]. With fatigue and stress related to unpredictability of bowel function, few things are seen to be worth the effort and the increased anxiety: *'We used to*

go out, walk, be out all day and yet, I can't do that. I can only go out, go out afternoons, [now] we go out, have a little stroll perhaps' [Ruby, CD, FL7].

Some participants sought to preserve a sense of normality and were prepared to compromise: *'Since I've had the chronic fatigue, I haven't been abroad, simply because a holiday is too many active days packed together ... so we have sort of short-ish breaks in this country, three or four days I can just about manage'* [Mark, CD, FL6]; while others wanted to have the full benefit of their time and energy investment: *'Travelling is something I'd like to do more, but if I go away, well I'm not going to make the most of it anyway because I'm too tired ... and I'd see it as a complete waste of money because I wouldn't be able to see the things I wanted to see and do things I wanted to do'* [Vicky, CD, FL8].

9.5.4 Personal relationships and significant others

Fatigue affected participants' roles as partners and parents, and their wider family relationships. Fatigue had a negative impact on participants' personal relationships: *'It's ruined it. ...It [fatigue] affects all aspects of my life. ... I can't be the husband I want to be ... I think the strain in our relationship has been massive, in fact it's incredible that we're still here [together] to be honest'* [Harry, CD, FL7]. Spending quality time together was affected by fatigue: *'I know I ought to have enough energy to stay awake, I don't think she [wife] likes when I fall asleep, she thinks it's a reflection on what I think of her company or something like that'* [William, UC, FL4].

Fatigue affected physical and emotional relationships: *'Our sex life has been quite drastically affected when my illness and my fatigue was quite bad, we weren't intimate with each other for quite a while'* [Laura, UC, FL6]. Some participants felt guilty that their lack of energy affects not just them but also people around them: *'I'm tired all the time, and I feel like that puts a lot of stress and strain on my partner as well ...You feel bad because your symptoms are actually affecting somebody else's life'* [Vicky, CD, FL8].

Those who were single at the time of the study, perceived fatigue as one of the main factors (the other one being IBD), that affected their confidence to establish a close relationship: *'I put up barriers quite a lot, I'm holding back a bit, I kind of shoot myself in the foot by doing that ... [but] in a way it's like I see myself as a bit of a liability I suppose, I think that there are plenty of people out there that would be understanding, that I could have a*

relationship with, but I think that it would be difficult to have a normal life with because of the adjustments that someone would have to make' [Hugh, CD, FL8].

Participants with parental responsibilities felt guilt for not being able to look after their children: *'I just feel - annoyed with myself, I keep saying frustrated because that's the way I feel all the time, it's just like I should be able to do things and I've got a twelve year old that's completely dependent on me getting out and about so if I can't do things it impacts on her'* [Catherine, UC, FL6]. A lack of energy and inability to function led to reversal of roles between parents and children: *'My daughter has now become my carer. It is a burden for her ... She's fourteen, she should be a child, she should have more time to herself'* [Sally, CD, FL8].

Some participants talked about their sadness that they are not able to take part in family activities: *'It is upsetting because I've lost a lot and missed out on a lot, but it's - this is really important this, it's as much my family that have been affected by all of this as me, it's not just me, there's a knock-on effect for my wife and my kids, and we're all affected by it in a big way'* [Harry, CD, FL7]. A sense of loss and regret at missed family opportunities was mentioned: *'Now they don't need me to play football with them, now my children have grown up, I'll never get that time back. Emotionally there wasn't any kind of relationship there with my kids'* [Gary, CD, FL8].

9.6 Living with fatigue: I am not the person I used to be

The last stage of data analysis in Moustakas' method (1994) is to create a composite textural and structural description of participants' experience. Moustakas emphasised that structures underlie textures and they are in a constant intrinsic relationship. It is therefore difficult to describe textures or structures in isolation from one another. This process of interlocking between texture and structure, as previously explained in Chapter 6, does not preclude from concentrating on either texture or structure at any stage of data analysis in order to gain clarity of the studied phenomenon. This iterative process of going between description, the 'what' of the experience of fatigue and the explanation, the 'how' or 'what does it mean' was utilised throughout the results chapters (Chapter 7, 8 and 9 up to this point). However, to achieve the full and detailed description of fatigue, each essence of its experience was explored individually. Now, in this fifth and last theme, to create fullness

of understanding of the studied phenomenon, the focus is on bringing the essences together to explicate the fatigue experience.

9.6.1 My daily battles - living with fatigue

Living with fatigue is a constant battle. From first thing in the morning, participants have to arm themselves to face fatigue and the struggles of the day ahead. Fatigue is invisible, unpredictable and frequently changing; therefore it is a difficult enemy to fight. To get through the day and achieve what participants would like to, they draw on their body and mind to provide them with physical and mental energy. Their body and mind become the participants' allies to help them get through the day. However, the mind and body are unreliable allies, as often they let participants' down by not providing a sufficient amount of energy. Small reserves of energy, or quickly depleting energy levels give space (open the gates) to fatigue - participants' biggest enemy. Participants' body and mind betray them and become allies to fatigue. When fatigue sets in, participants' daily plans are usually doomed to failure. The result of these battles is at best a compromise along the fight-surrender continuum – with participants having to reduce the activities, but usually a crushing defeat with them having to give up on their plans.

The outcome of this defeat is that participants need to stop and rest. If they want to stand any chance of continuing the battle and get on with their daily life on that day or the following day, participants need to rearm themselves. This process of rearming means they have to take a break and rest. Being defeated or rearming look the same, that is, participants need to sit or lie down to rest. However, the root cause of this is different: being defeated means **having** to rest, whilst rearming is a deliberate, tactical decision of **wanting** to rest. Participants, and not fatigue, are in control and are the decision-makers.

Some participants are not prepared to face the daily battles and constant defeats, therefore they surrender to fatigue: *'What's the point of me doing anything? What's the point of me even getting up in the morning?'* [Alan, CD, FL10]. Others, who have lost their confidence, are afraid of it: *'It is the fatigue, that lack of energy that is so scary'* [Ruby, CD, FL7]. The resignation to the perceived inevitability of defeat makes participants restrict their lives and retreat into 'little lives'. This is a life characterised by a lack of motivation, a reluctance to instigate or an inability to complete things.

Being defeated in the daily battle with fatigue, or giving in without a fight, means not being able to live life as participants would want to. Participants feel that they are being punished

by being deprived of their life and freedom. The severe form of that punishment is not even being able to go out of the house, which equates to imprisonment and an inability to make short or long-term plans: *'I don't go out much. This room is where I spend most of my time'* [Harry, CD, FL8]. Therefore, fatigue robs participants of their previous life, as it was before the onset of fatigue. They are unable to have normal, everyday lives in terms of education, going out and socialising, family relationships, things that used to be taken for granted.

Every day, their life becomes smaller and smaller, increasingly limited in everything that they do. This results in isolation, frustration and anger, and a feeling of resentment to the root causes of their problems – their IBD and fatigue. At times the resentment is aimed at others e.g. family, friends, healthcare professionals, but most frequently it is aimed at themselves, for being weak and unable to cope. This leads to negative self-image, low self-esteem and a loss of one's 'previous self': *'I am not the person that I used to be [and] I'm not the person I would like to be'* [Vicky, CD, FL8]. This leads to a sense of grief and a resistance to accept the 'new self' and a loss of any hope for a return to the previous energetic self, and the person who is able to make plans, be reliable, enjoy life, make commitments, do things because they can, or make a conscious decision to rest – decisions that are made by the individual and not by fatigue.

9.6.2 Being in and out of control

Participants perceive fatigue as complicated, complex and dynamic and use a variety of terms to describe it. The diversity of terms used reflects and confirms its complicated nature, but does not help to explain fatigue. Participants had great difficulties describing fatigue as they themselves did not understand it. They do not know what they are fighting – the fatigue or themselves – and they could not explain things to others, leading to being misunderstood and not believed.

Fatigue could be seen as a way that IBD communicates with the person through their body, requiring them to rest and recuperate. However resting even for long periods of time does not bring the desired effect, which is a reduction of fatigue. Periods of rest do not help to fully re-charge their energy. Participants feel they need to find different ways to understand their body and to do different things to their body for it to function better. Fatigue uses different tactics of attack (as presented in Chapters 7 and 8), striking at different time of the day or week, with different severity and duration, and leaving participants unprepared or ill-equipped for the next attack. Some participants did not know about fatigue, or were

told that if IBD is in remission they should not have fatigue. This makes them feel weak and a failure. Participants feel trapped – they are too weak to find a way out, they have no physical or mental energy or motivation to persevere – and this leads to them failing in their actions or not even starting: *'You've tailored your life to do a lot less than you did five years ago, and although you go through a day well you think, "Oh I had a really good day yesterday" but actually compared to ten years ago, I didn't do very much'* [Mark, CD, FL6].

Participants see this as multiple entrapments as they are locked in their failing body and trapped in a situation of not knowing what to do, and being disbelieved. Therefore they see themselves discredited as a person. Another entrapment is IBD, because that restricts their daily lives – they have to be near a toilet so this controls how far they can venture. They are also restricted by their diet which affects their going out and socialising by not being able to have a meal out or drink alcohol with friends. Participants often perceive themselves as being 'taken hostage' by fatigue. They then try to free themselves, but the methods available to them are unreliable and ineffective. Advice on different strategies to fight fatigue was limited or not forthcoming from anyone, including healthcare professionals.

Restricted energy levels led participants to put their life on hold: *'Like I am at the minute, just waiting for it [fatigue] to get better and I don't feel like I've got any control over it'* [Vicky, CD, FL8], or trying to fit their life to match their energy level: *'My life's so limited, I sort of shrunk it down so it's manageable now'* [Ruby, CD, FL7]. Despite attempts to overcome the effects of low energy, some never feel that they are quite 'on top of things' and as a result try to reduce their life to a manageable size. There are reversed dimensions between fatigue and participants' lives, with fatigue being disproportionally large, and their lives constantly getting smaller, like a prison cell. Some participants feel that they are not able to make plans as fatigue makes them feel not in control of their body, leading to the perception of self as unreliable.

Fighting fatigue is like fighting an invisible enemy: *'It's like a demon inside me'* [Alan, UC, FL10], to others this may seem as a non-existent enemy. Those, such as healthcare professionals, who could validate the existence of this invisible enemy – fatigue – did not do so, leaving participants doubting themselves: *'I felt that it was just me, just me being silly, just me you know. I was making it up, it wasn't real, but I did know it was real, because it feels real'* [Sue, CD' FL9].

The most frequently used method for rearming or preparing themselves for the next battle is rest; to others it looks as if they sit down and do nothing, and may be perceived as being lazy. The loved one's questioning the prolonged period of rest becomes, in a way, an ally to fatigue and not on the participants' side. In instances where loved ones try to understand and help, participants may not want their help, as they want to be independent and do things for themselves. If they accept help from others, it may mean that they are no longer in control, with others deciding what and how things will be done, resulting in participants surrendering their freedom.

The unpredictable nature of fatigue contributes to a downward spiral of negative feelings: *'It's uncertainty I suppose, not knowing whether it's going to get any better, and then you have this struggle with myself. I think that's a snowball effect of not knowing how your body's going to react. ... I'm convinced I'm not going to get any better, so I'm trying to come to terms with that. I try not to think too much if I can get away with it, because then I get really down and fed up and what's the point'* [Ruby, CD, FL7]. Ruby does not know her body anymore and she cannot trust it. Her unreliable body makes her an unreliable person – and this creates the negative self-image and lack of control.

Fatigue leads participants to create a new less valued self-image, that of a person lacking confidence, doubting themselves and unable to remember things and feeling useless. Living everyday life is often embarrassing as they are no longer able to honour and fulfil their expected roles and responsibilities. Participants cannot rely on their body and others could not therefore rely on them.

9.6.3 Quality of life

Participants' perception of high quality of life equates to having a choice of doing what they want, when they want and not feeling completely exhausted most of the time: *'Good quality of life for me is simply being able to be more active. Being able to not have to think twice about really silly things ... [and] not having to always think about the consequences of any everyday thing that you do ... I'm not saying I want to go out in the evenings, but it would be nice to feel well enough that you could've gone out in the evening if you wanted to'* [Julie, UC, FL9]. Having choice is seen as very important: *'Quality of life, I feel like that's been taken away really, by the Crohn's and the fatigue. You can't do the things you want to do, you can't see the people you want to see, you don't want to do anything but sleep, I don't think you've got a lot of quality of life'* [Vicky, CD, FL8].

Poor quality of life is seen as leading a very restricted life and being deprived of choice: *'I just about struggled to do a day's work, I'd come home, and really all I had the energy to do was go to bed to get ready for the next day, and the same at the end of the week. ... And eventually you get to the stage where you think, well this is not right, this is not what life is about, there's something wrong here'* [Mark, CD, FL6].

Some participants feel that fatigue has a more severe and devastating impact on their quality of life than other symptoms of IBD because they do not know how long it will last: *'There's no end in sight. The fatigue probably affects me more than others [symptoms], because the fatigue goes on for longer, and it stops me from enjoying things that otherwise I would be able to enjoy'* [William, UC, FL4].

9.6.4 Trying to preserve a sense of normality

Participants hoped to regain a sense of normality: *'Just trying to live what I consider a normal life, so how I was before I was ill, so being able to get up in the morning, feel refreshed, being able to go to work and come home and still have energy to visit friends and family. ... I want to be able to get back to doing all the things I was doing beforehand, that to me is normal'* [Laura, UC, FL6]. However, fatigue and limited amount of energy make participants feel inadequate as a person, as if they have lost their capability to function independently and have aged before their time: *'It's frustrating, [boyfriend] shouldn't need to look after me at 24, and he's 25, he shouldn't have to look after his 24 year old girlfriend, that's for when we're in our 70's'* [Vicky, CD, FL8]. Both physical and mental functioning is affected: *'I just haven't got the mental energy to focus on what I need to do. And sometimes, you know most times it doesn't bother me because my brain's just half asleep, and I think well, fine, whatever, but then every so often it'll poke me and say "Oh, you should be doing something more with your time"'* [Sophie, CD, FL6].

Image management is part of trying to preserve a sense of normality by some participants: *'People can be a bit funny, they don't understand why you won't turn up at a party, and why you don't fancy, because you're absolutely shattered, and of course you can't say I'm too tired to turn up because it seems a bit weird, so you have to say 'Oh I've got a cold' or something'* [Louise, UC, FL5]. Fatigue is not perceived by family, friends and acquaintances as a legitimate reason to interfere with people's life plans, and therefore participants themselves try to create an image of normality and avoid being labelled antisocial and therefore stigmatised and excluded. For others, their social reputation is less

of an issue: *'I'm not bothered, not really any more, I think people around me that know me now, are used to me getting a bit tired and dozy'* [Fiona, CD, FL7].

Participants are afraid of the ramifications of their actions on the severity of their fatigue if they over-do things and try to live their normal lives: *'If I want to go and dig in the garden, not having to think 'Oh well, can I?' Will I be able to last more than ten minutes, will I achieve what I'm trying to do here, or will I just be exhausted the whole time? ... Not that I want to go and dig, but it would be nice to have the choice'* [Julie, UC, FL9]. This constant internal conflict, between aspirations and reduced expectations as an effect of losing to fatigue, is ever-present: *'I would be more willing to like push myself to be out there and chase your dreams a bit more rather than feel that you're having to settle for second best in a job or any kind of job that you're not enjoying'* [Hugh, CD, FL8]. The 'new normal' is different to their 'normal' before fatigue: *'I was spending most dinnertimes – nobody knew this - I would go and sleep in the car, in the car park and there's loads of ways in which I've had to adapt to the fatigue side of things'* [Harry, CD, FL7].

Constant fatigue, difficulties in being self-sufficient and having to give up many things in their private, social and professional lives make participants feel guilty for not reaching their goals and their full potential: *'I used to get really, really angry and frustrated at not being able to do what I want to do, I'm just this little person who sits in the house'* [Ruby, CD, FL7]. Participants who try to get out of the stagnation, find themselves going around like on a carousel: *'I don't think I'm a lazy person, but sometimes I feel, for goodness sake, get a grip ... I'd just like to be able to get going and get on with things, get a job and get my life together, but I just seem to be on this treadmill of nothingness, in a rut'* [Catherine, UC, FL6].

Trying to have a normal life could equate to an analogy of saving and then spending money – in this case energy. Participants have to accumulate a stock of energy before their activities. Despite those savings, they do not feel that they are getting 'value for money' as the limitations inflicted by fatigue affect what they do, and they continue to repay the debt by having to rest to regain energy for many days afterwards.

9.6.5 The new fatigued me

Participants often compare themselves how they were **before** fatigue, with the way they are **now** with fatigue. This 'new fatigued me' image makes them realise how much they have lost: *'I was a very active bubbly person, whereas now I feel like it's kind of taken that*

away from me because I'm too tired' [Vicky, CD, FL8]. Fatigue presented as subjective, invisible and nebulous, makes participants doubt themselves and the symptoms. In Chapter 7 fatigue presented as a product, a process and the outcome is also visible here in this chapter in its many different forms through the impact on people's lives. Fatigue as an ill-defined product makes people afraid, as a process it drains people of energy, and as an outcome leaves them angry, frustrated, depressed, lacking energy and not achieving their potential. The life of a fatigued person is like a vacuum: *'It's an emptiness of spirit if you like, it is extremely depressing and you just have to give way in the end, and just shut your eyes and go to sleep, it's the only thing you can do'* [Robert, CD, FL4]. Participants blame themselves for not being strong enough to cope: *'I wish that I could just not be me for a day so I could have a break from everything that the Crohn's gives you. Just I don't know what to do to make the pain and the tiredness and all these tests and everything stop. I think it's the thought that knowing that it won't stop, it's a lifelong thing, you can't change it or cure it'* [Fiona, CD, FL7].

Severe fatigue over a prolonged period of time and realisation of the extent of loss due to fatigue causes participants distress: *'Fatigue's the worst symptom, most distressing symptom, I can deal with the running to the toilet, but it's the fatigue, it's the one what's destroyed my life really, changed my whole life'* [Ruby, CD, FL7]. Fatigue is like an alien that invades people's body and devours and destroys their most valuable and precious possessions – them and their life: *'My husband gets really upset, because the fatigue affects every single thing ... and it's taken him and me probably, but him definitely up to this year [she was diagnosed 6 years previously] to accept the fact that I'm different. ... I think I've accepted it a bit more, but it's taken my husband a lot longer, I still don't know whether he can, I think he thinks – I still want me back, but I definitely think he wants me back'* [Ruby, CD, FL7].

Despite feeling that their body and mind are failing them, some participants try to remain optimistic: *'I still see myself as a lucky person and I have a very strong sense of personal optimism, I'm happy to be alive despite every part of your body going'* [Julie, UC, FL9]. For others remaining positive is another lost battle: *'I try to think on the positive, but I've had a lot of depression with this ... and I'm frightened and I'm worried. So when I look at things like that it upsets me a lot, but I don't focus on it, because if I focus on it too much I get too upset and depressed because I can't do what I want to do'* [Harry, CD, FL7].

For some participants a way forward in living with fatigue is to restrict their life, prioritise and accept help from others. While for others, this only creates a sense of loss and frustration – this is a wasted life, a life not worth living: *'I don't want to sit down and watch television, I want to do something, whatever, but lethargy comes into it. Lethargy, morose, that sort of tiredness, not physically tired, not that you've been doing anything because you don't actually do a lot'* [Roger, CD, FL5].

The lack of understanding of fatigue makes participants feel lonely and isolated: *'I'm exhausted and you just feel alone, nobody to help, like you're kind of, you're in the middle of a crowd screaming for help but nobody's listening, everybody's just going, grin and bear it, you'll be fine there's nothing wrong with you'* [Fiona, CD, FL7]. Feelings of isolation and loneliness are reinforced by participants feeling they are being ignored and not being listened to or receiving emotional support from others, including healthcare professionals: *'There isn't the acknowledgement and there isn't the support. I feel like I've been banging my head against a wall for years, but I've told them [medical and nursing staff], because it's relevant - it's what I have to live with'* [Harry, CD, FL7].

Fatigue jeopardises participants' perception of their identity: *'Work's all I've kind of got left to focus on as me, as part of who I am, my work is who I am I suppose in a lot of ways, and I've always wanted to work'* (Vicky, CD, FL8). Those who prioritise their life to a manageable level, feel that their life is very restricted, that it is more of an existence rather than living quality life: *'I keep myself going by saying at least you're looking after yourself, you don't have to ask anyone to do anything for you, you can keep yourself clean, you can keep the house relatively clean, but it's like I'm thinking about my Mum, my Mum's 80 [Ruby was 50 at the time] and that's what she does you know! Where I should be able to do so much more'* [Ruby, CD, FL7]. Asking for help or accepting help from others is an evident sign of defeat.

None of the participants perceive fatigue as positive e.g. an opportunity to rest; they see fatigue as negative, limiting and destroying their lives. and only few are able to make a positive adaptation: *'It took me a long time, and I had to get my head into a good place, I've made some really nice friends that just like me for who I am now. They didn't know me before I was ill, so it doesn't bother them that I am ill.... They're all over the country, I met them all online, in forums and chatrooms and stuff, and I've met them in person as well now, and they're lovely. I never thought I could have that, and it's amazing and I speak to them every day and it's just lovely'* [Fiona, CD, FL7]. Some participants also try to adjust

their social life and come up with new solutions: *'I've sort of had to be a bit more flexible, we tend to invite people round for dinner now and do things in the house rather than go out and about ... I try and keep in contact with people through the internet, Facebook, things like that'* [Laura, UC, FL6]. While for others lack of face to face contact is seen as second best: *'I play on the computer a lot, an online role-playing game, so I get to chat to people on there, but it's usually about Endgame stuff, it's nice but it's not real human contact'* [Sophie, CD, FL6].

Despite fatigue-related frustration, participants try to remain hopeful that help may be found: *'I'm going to get angry and then I'll lash out at it, but I'm not going to accept that [fatigue]'* [Alan, UC, FL10]. Some are hoping that one day they would be strong enough to defeat fatigue, some are hoping that one day fatigue would go away, while others are hoping that IBD will be better managed, solutions for fatigue will be found through science and someone will help them to get out of this *'treadmill of nothingness'* [Sally, CD, FL8] and of a life controlled by fatigue.

Horizons of life with fatigue means leading a very limited and restricted life: *'I did feel like I was wasting my life. It made me feel old'* [Henry, UC, FL8]. Time was passing and people have only a limited amount of energy: *'Even on a normal day, when I am normal, my energy levels are low, they're not high'* [Sue, CD, FL9]. The 'new normal' is to be fatigued, only to have enough energy to get through the day: *'When I'm fatigued, basically I don't go out of the house much at all because I don't have the energy'* [Harry, CD, FL7]. Unpredictability of fatigue makes planning difficult, or people have to plan things to the smallest detail, leading to living a micro-life: *'Well, with no energy I had to plan everything in advance, if I'm going to do this at that time, I take that medicine at this time, well is it worth it, go through all this hassle to do what everybody else is doing at the drop of a hat'* [Hugh, CD, FL8].

Some question what they have done wrong, why are they being punished: *'I've always kept myself fit you know, and it just – why me? I suppose that's what I'm saying, is 'why me?''* [Andrew, UC, FL6]. Living with fatigue *'grinds you down [but] 'you can't stay in bed all the time, you've got to get up, you've got a life, you have to live it as best as possible, but it is very difficult because I'm dragging myself around'* [Sophie, CD, FL6]. People grieve for their lost self and their life before fatigue: *'I just want my life back, what I had before. ... I'd want to get my fitness back. ... My life just gets smaller and smaller and just have to give up'* [Ruby, CD, FL7]. They cannot have their previous life back; they cannot fulfil

their roles as they were before fatigue: *'Be able to go out and enjoy things with my children, as and when they want me to...But I can't do that'* [Sally, CD, FL8]. Participants have lost their previous life and their former self, but are unwilling to accept the 'new fatigued me' and their new life limited and controlled by fatigue: *'I'm kind of becoming more and more incapacitated, and less able to do stuff, not being able to get on with the kind of things I can normally do'* [William, UC, FL4].

Many explain that fatigue makes them feel as though they are a different person, angry and frustrated: *'I've noticed over time, I can be really short-tempered and really unpleasant. ... That is frustrating because that is not me, that is fatigue'* [Julie, UC, FL9]. Constant fatigue, difficulty being self-sufficient and having to give up many things in their private and professional lives makes participants feel guilty for not reaching their goals and their full potential: *'I used to get really, really angry and frustrated and upset. ... I wouldn't enjoy things, I'd be irritable, snappy, I'd just, total waste. ... [I'm] frustrated at not being able to do what I want to do, I'm just this little person who sits in the house'* [Ruby, CD, FL7].

9.7 Summary

For pragmatic reasons, namely depth of description, the effects of fatigue on individuals' lives are presented in relation to specific aspects of functioning. In real life however, fatigue often affects many aspects of people's lives simultaneously and initiates a chain reaction. The multifaceted aspects are discussed towards the end of the chapter, where the combined effects of living with fatigue are presented.

This chapter provides insight into the impact of fatigue on the lives of individuals' with IBD. As outlined, the consequences of fatigue are far-reaching and encroach on all aspects of a person's life. In this study, the impact of fatigue and its consequences were predominantly presented as negative, limiting and damaging to the individuals experiencing it and destroyed their quality of life.

Heterogenic characteristics of individual participants provided different and far-ranging descriptions and insights of fatigue impact. The common elements of fatigue affected different aspects of everyday life covering physical, psychological, cognitive and social functioning. The areas of impact and the extent to which people's lives are affected varied from one individual to another. Factors such as fatigue severity and its duration played an

important role in the extent of fatigue impact, forcing people to make changes to the way they lived and develop new ways of functioning. Diversity and ambiguity regarding the concept of fatigue (Chapter 7) and the vast range of factors affecting fatigue and management methods (Chapter 8), were evidenced in this chapter through the diversity and range of the fatigue impact. The negative impact of the fatigue experience was reflected in the pessimistic and negative coping strategies adopted by the participants.

Chapter 10 Discussion and conclusions

10.1 Introduction

The study aimed to explore the experience of fatigue in people diagnosed with IBD. To this end analysing the lived experience of people affected by this symptom was deemed to be the essence of the study. The aims of this chapter are to:

- Critically discuss the study results on IBD-fatigue in light of the literature reviewed in Chapters 2 and 4, and the wider literature on fatigue in other chronic conditions
- Compare and contrast the similarities and differences of the symptom of fatigue across the conditions
- Provide a critical analysis of the methodology and methods used to study fatigue
- Make recommendations for further research and clinical practice in the area of IBD-fatigue.

To impose structure on this chapter, the discussion is loosely organised around the study findings (Chapters 7, 8 and 9) and the study methods (Chapters 5 and 6). Presenting the discussion this way will help the reader to follow the structure of the information related to the phenomenon of IBD-fatigue.

10.2 The key empirical findings

The aims of the study, to explore and describe the phenomenon of fatigue, have been achieved. The study allowed the widening of the horizons, description and understanding of fatigue. The key findings relate to description, contributors and management, and the impact of fatigue on participants' lives.

10.2.1 Phenomenon of IBD-fatigue

The essence of the phenomenon of fatigue and its detailed description reveals its complex and complicated nature. The challenge to understanding fatigue was reflected in the difficulties that participants had in describing it. This was evident in participants' use of wide-ranging terms, incorporating similes and metaphors. It was unclear whether these

words had specific meaning for the person using them. It was possibly their best attempt to illustrate their own experience of fatigue. These descriptors led to the identification of components of fatigue that are common: types, dimensions, severity and pattern; and specific: individual's experience and fatigue impact on their life.

The symptom of fatigue was identified in three different forms: as product (having fatigue), as process (being fatigued) and as outcome (feeling fatigued), but it was impossible to reach a conclusion as to whether these three different forms of fatigue were different entities or whether they were componential parts of one thing. Use of different forms of language e.g. nouns (passive form - an object), verbs (active form - process) and adjectives (severity or feelings - outcome) would indicate an existence of the different forms of fatigue. So far no studies exploring fatigue analysed the use of different forms of language as a means to understand the studied phenomenon and its experience.

Fatigue as a symptom is invisible. One can only see its presence by the ways participants were affected. Its invisibility and highly fluctuating pattern may lead to others questioning the authenticity of its existence.

10.2.2 Contributors to fatigue and methods of managing fatigue

A range of physical, psychological, cognitive and situational contributors were identified. Within each category of contributors, additional sub-categories existed. This demonstrates the multifactorial composition of fatigue. For each participant, a variety of factors were present in different combinations and intensities, possibly resulting in different individual experiences of fatigue. Some factors had a direct and others an indirect impact on fatigue.

Different categories of management methods tried by participants were reported: physical, psychological, cognitive and situational, with further sub-categories within each. Most of these were ineffective or only had a short-term benefit in alleviating but not eliminating fatigue. This could be due to the fact that there is a paucity of evidence on the effectiveness of management methods, including the time-period, combination or intensity of method to be used. The methods used by participants to manage fatigue were therefore experiential and not evidence-based.

10.2.3 Impact of fatigue on individuals life – loss of self

Fatigue was identified as impacting on all aspects of individuals' lives, limiting and stopping activities and roles, and leading to fundamental changes in people's range and types of activities.

The impact of fatigue was perceived to be mostly negative, creating negative emotions of anger, frustrations and leading to participants adapting to a negative self-image of low self-esteem and failure. Participants were more inclined to talk about what they no longer could do, rather than what they were able to do. Life with fatigue is a daily battle, with participants constantly moving along the **fight-surrender continuum**: striving for control but being frequently defeated by fatigue and not being in control of their day-to-day lives.

The individual's fatigued mind, body and self function independently of each other in an unpredictable, uncoordinated and un-unified way. Fatigue invades the individual's mind and body, turning them into a person that they do not want to be. Participants try to adapt their life by either fighting fatigue or reducing the range and type of activities. Both strategies have negative outcomes, the constant battle with fatigue makes participants emotionally and physically exhausted, while reducing activities leads to a restricted and limited life. As a result participants have 'little lives'. Participants feel as they have lost their lives and have become old before time.

They grieve for their previous 'self' and for the loss of their previous active and independent lives. Participants' reflection on the loss of their previous life and previous self, results in them adopting a negative image of a life with fatigue and not accepting their new fatigued self. This can lead to emotions of anger, frustration, depression, and a resentment of others and self-blame for being weak.

10.3 Analysis of study findings in light of the wider literature

Understanding the different components and the composite experience of IBD-fatigue discussed in this chapter and compared against wider literature, contributes to a greater understanding of this phenomenon and its impact on individuals' lives.

Whilst fatigue in some conditions was epitomised in qualitative and quantitative work (Ahlberg *et al.* 2005, Falk *et al.* 2007, Alsén *et al.* 2008, Kangas *et al.* 2008, Radbruch *et*

al. 2008), the limited available evidence on IBD-fatigue was predominately quantitative (van Langenberg & Gibson 2010, Czubier-Dochan *et al.* 2013a). However, in light of the paucity of IBD-fatigue evidence on both qualitative and quantitative sides of the paradigm, it was necessary to venture further afield into other chronic conditions to examine the findings of this PhD research.

An updated search of literature on IBD-fatigue run on 12 June 2015, utilising the search strategy presented in Chapter 2, resulted in 25 additional references published since the first review (3 August 2012). The summary table of the new papers is presented in Appendix XXIII, and the studies' findings are incorporated into the discussion. Of the 25 studies, three were testing effectiveness of interventions on fatigue: thiamine (Costantini & Pala 2013), solution focused therapy (Vogelaar *et al.* 2014), and physical exercise, omega-3 fatty acid, dietary advice and placebo (McNelly *et al.* 2015). Three studies were qualitative of which two were conducted with individuals diagnosed with IBD (Beck *et al.* 2013, Czubier-Dochan *et al.* 2013b) and one with HCPs (Czubier-Dochan *et al.* 2014a). One study employed population based cohort design to assess fatigue course and contributing factors longitudinally (Graff *et al.* 2013), one study was mixed-methods design to develop and to refine psychometric properties of an IBD-fatigue scale (Czubier-Dochan *et al.* 2014b). The majority, 17 studies, were cross-sectional surveys (Banovic *et al.* 2012b, Banovic *et al.* 2012a, Jelsness-Jørgensen *et al.* 2012b, Castillo-Cejas *et al.* 2013, Goldenberg *et al.* 2013, Vogelaar *et al.* 2013, Cohen *et al.* 2014, Kappelman *et al.* 2014, Opheim *et al.* 2014a, Opheim *et al.* 2014b, Pellino *et al.* 2014, van Langenberg *et al.* 2014, van Langenberg & Gibson 2014, Yoo *et al.* 2014, Grimstad *et al.* 2015, Norton *et al.* 2015, Vogelaar *et al.* 2015).

The topic of fatigue in IBD has been attracting greater interest in research over the past three years. Studies were designed specifically to test effectiveness of interventions on fatigue, the IBD-fatigue scale was developed with individuals diagnosed with IBD, and numerous cross-sectional studies investigated prevalence, impact of fatigue, and factors associated with fatigue contributing to the development of a much stronger body of evidence. Findings from qualitative studies with patients established that IBD-fatigue has a considerable negative impact on individuals' lives (Czubier-Dochan *et al.* 2013b) and a study with HCPs confirmed that fatigue is either not recognised as a priority, or is not effectively managed due to absence of effective management strategies (Czubier-Dochan *et al.* 2014a).

The knowledge and understanding of the phenomenon of IBD-fatigue gained from this study has been compared and contrasted against the wider literature on fatigue in IBD (Chapter 2) and selected chronic conditions – cancer, MS and RA (Chapter 4). The literature on fatigue in other chronic conditions (e.g. stroke, HIV, diabetes mellitus and others) is also utilised to provide the different platforms for interrogation of new evidence from this qualitative study. Examining accounts of fatigue from other chronic conditions provides varying perspectives of experience. This allows the achievement of greater clarity in answering the questions: ‘what is fatigue?’ and ‘what does it mean?’ as an attempt to satisfy connections both within and between the data and the world outside.

10.3.1 Description and meaning of fatigue

10.3.1.1 Comparison of the description of IBD-fatigue with fatigue in other chronic conditions

In IBD, there was a wide variety of terminology used to describe fatigue and a comparison across all conditions demonstrated a similarity and interchangeability of terms employed (Table 10-1). This variety reflects the multidimensional, complex and convoluted nature of fatigue.

Table 10-1 Descriptors of fatigue across different conditions (examples)

IBD-fatigue literature review*	IBD-fatigue present study**	Cancer, MS and RA***	CFS and other chronic conditions [†]
Tiredness	Exhausted	Tired, worn out	Exhausted
Reduced energy	Knackered	No energy	Lack of strength
Heavy as lead	Heavy as lead	Total wipe out	Heavy body
Physical depletion	Like having flu	Can't be bothered	Losing energy
Feeling of exhaustion	Like energy just draining out	Like energy drained from me	Wearing a wet, heavy coat
Reduced muscle strength	Running a marathon every day	Battery just run dry	Hard to walk upright
Unpleasant	Hitting a brick wall	Hit by a tidal wave	Jaded
Excessive whole-body tiredness	Head feels like mush	Memory problems	Walking in slow motion
Decline of vitality and vigour	Woolly and fuzzy head	Unable to concentrate	Uncontrollable feeling
Reduced vitality	Just a zombie	Like a vegetable	Weak and dizzy
Cognitive impairment	Like a demon inside me	Like a zombie	Sudden need to lie down

Key: *Czuber-Dochan *et al* 2013a; **Data from the present study; ***Stuifbergen & Rogers 1997, Porock & Juenger 2004, Hewlett *et al* 2005, Bennett *et al* 2007, Mills & Young 2008; [†]Larun & Malterud 2007, Alsen *et al* 2008, Power *et al* 2008, White *et al* 2012.

Fatigue across conditions was presented as subjective, with physical and mental facets, fluctuating, and above all invisible. This invisibility often leads to the existence of fatigue being questioned by self and others. Most descriptions of fatigue focused on an overwhelming sense of exhaustion or tiredness encompassing the whole body, and the sudden, unpredictable and uncontrollable nature and severity of fatigue. Furthermore, the terminology used reflected a diminution in the ability to function in physical and/or cognitive aspects of life.

The definitions of fatigue presented in literature on MS, cancer, RA, chronic heart or lung disease, CFS and other conditions, all relate to the same characteristics, namely to its subjective, excessive, persistent and abnormal nature, reduced energy and muscle strength disproportionate to level of activity, impacting daily physical and cognitive functioning and leading to impaired quality of life (Fukuda *et al.* 1994, Ream & Richardson 1996, Wessely *et al.* 1998, Kapella *et al.* 2006, Falk *et al.* 2007, Alsén *et al.* 2008, Power *et al.* 2008, Bol *et al.* 2009, White *et al.* 2012). All these characteristics are included in the definition of fatigue in the International Classification of Diseases (Cella *et al.* 2001).

However, the terminology describing fatigue was used inconsistently, creating a lack of clarity in the meaning of the phenomenon of fatigue. The absence of adequate and commonly-understood terminology for fatigue, and a lack of understanding of fatigue by others, means that discussion often takes place using similes and metaphors, discussed in the next Section 10.3.1.2. Across all conditions, the overwhelming sense of exhaustion affecting the whole body was reflected in terms such as '*knackered*', '*worn out*' or '*excessive whole-body tiredness*' (Porock & Juenger 2004, Hewlett *et al.* 2005, Power *et al.* 2008, Repping-Wuts *et al.* 2008). The unpredictable nature of fatigue was expressed by descriptions such as: '*like a demon inside me*', '*sudden need to lie down*' or '*uncontrollable feeling*'. In view of its intangible and illusive nature, terms such as '*heavy as lead*' or '*wearing a wet, heavy coat*' seek to place fatigue within the context of everyday life, a desire to make it better understood by others (Larun & Malterud 2007, Alsén *et al.* 2008, Power *et al.* 2008, White *et al.* 2012). However, the use of everyday language has the effect of 'normalising' the pathological symptom of fatigue, for which individuals should be receiving help and support.

IBD-fatigue has a negative meaning for individuals, which may lead to a lack of acceptance and a failure to adapt their life to a new reality. As in other conditions, IBD-fatigue has to be acknowledged as one of the symptoms of that condition. This should validate the

authenticity of IBD-fatigue for patients and potentially lead to more proactive and earlier health-seeking behaviour and positive adaptations.

10.3.1.2 Role of metaphors in describing the symptom of fatigue

To understand the experience of fatigue as lived, HCPs need to understand the individual's experience. The use of metaphor provides the means of interpreting this experiential 'lived-world' (Coulehan 2003). It allows to seek an understanding 'beyond words', providing a focus on the meaning of that word – and not the word itself.

All words have a meaning ascribed to them by society which is embedded within the context of the speaker (Czechmeister 1994). Metaphor always has a double meaning – *literal* and *literary*. *Literal* or semantic provides logical clarity in describing things as they are, whilst *literary* or poetic is embroidered with feelings – that is *not* that object, but it is *like* that object, reflecting the characteristics and emotions relating to that object (Crocker 1977). When a person is described as a 'gem' they are not hard and inanimate, but precious and valuable to know (Sapir & Crocker 1977). A metaphor may be idiosyncratic to the individual user, or represent a commonly-shared meaning. Only the person using the metaphor knows which characteristics they are referring to. Cultural factors may also affect the meanings of metaphor.

In her book *Illness as a Metaphor* (1978), Sontag presented illness as a medically defined disease with a biological cause, a combination of biochemical imbalance and pathophysiological processes. Whilst she perceived metaphors as fundamental to individual and collective expression, if an individual is seen purely through a biomedical model, Sontag saw no need for metaphors. She also warned that the use of metaphors has the scope to create loss of meaning, confusion, stereotype and stigma (Sontag 1978). Lieban (1992) also states that if metaphors lead to negative stereotyping, their effects can be a powerful symbol of devaluing the individual.

The person, however, is more than a combination of biological systems and physiological processes and to treat the illness it is necessary to treat the whole person - attending to their symptoms and emotions (Kirmayer 1992, Czechmeister 1994). Metaphors are a symbolic interpretation of these symptoms and emotions, and treatment should start with conversation to find out from the individual themselves how it feels to be affected by these symptoms.

The descriptions of IBD-fatigue extrapolated from this study compared with descriptions of fatigue in other chronic conditions shows a use of similar terms including an extensive use of metaphors. This analysis confirms that fatigue is being described in a similar language. Whilst the experience of fatigue may be similar, the extensive use of metaphors to describe it does not provide greater understanding of this symptom.

Participants described IBD-fatigue using many different metaphors as they sought to communicate the complexity and their lack of understanding of the phenomenon. Metaphors relate to a subjective, imperfect capture of individuals' lived reality (Benner & Wrubel 1989). Each metaphor offered the risk of a different interpretation, resulting in the blurring of the overall understanding of the phenomenon.

10.3.1.3 Fatigue as a discrediting and stigmatising symptom

Fatigue as a symptom is debilitating and distressing. It impacts on all aspects of an individual's life, limiting and stopping their activities and roles. The characteristics of fatigue e.g. its fluctuation, invisibility and unpredictability may lead to stigma. Goffman (1963) defines stigma as 'an attribute that is deeply discrediting' where the stigmatised person is reduced 'from a whole and usual person to a tainted, discounted one' (p. 3). Stigma is socially constructed and at its essence devalues the individual's (or group's) social identity (Crocker & Quinn 2000).

Stigma is associated with many chronic conditions such as cancer, CFS, mental health, HIV or IBD, where the individual's characteristics are perceived to be flawed or spoiled by the disease (Jones *et al.* 1984, Fife & Wright 2000, Åsbring & Närvänen 2003, Lebel & Devins 2008, Taft *et al.* 2011). The nature of chronic conditions results in tainting the individual, depriving them of their previous social identity and replacing this with one that is less valued (Crocker & Quinn 2000).

In the case of IBD, the sources of stigma include a higher than normal frequency of going to the toilet, refusal to eat certain food, loud stomach noises, problems with bowel control, whilst in the case of IBD-fatigue, stigma results from physical weakness, cognitive limitations, sleeping during the day, reduced participation in social events and an inability to fulfil certain roles in an individual's personal and professional life. Individuals see themselves being dismissed as unreliable, irresponsible and untrustworthy and are ascribed a devalued social identity (Crocker & Quinn 2000). Furthermore, individuals with fatigue often feel that their experience is not validated and disregarded as an emotional issue

(Looper & Kirmayer 2004). This leads to the feeling of being stigmatised by others who doubt the existence and fluctuating severity of the symptoms, often resulting in the person's character being questioned and the symptom attributed to psychological causes (Crocker & Quinn 2000).

Stigma has been presented as consisting of a number of different components: labelling, stereotyping, separation, emotional reactions, status loss and discrimination (Link & Phelan 2001, Link *et al.* 2004, Ottati *et al.* 2005). These components were present in the experience of fatigue as described by individuals with IBD.

In the case of labelling and stereotyping, the illness and its impact can become the permanent characteristics of an individual (Longmore 1985). This has potential for generalisation of the characteristics of the illness to the person. The condition becomes the individual, for example, a person becomes a 'blind person' or a 'one-legged man' (Zola 1993, p.168). In the case of IBD-fatigue, it is not that the individual is fatigued, and fatigue can be addressed, but fatigue is used to label the person as lazy, weak, inadequate and a general failure. This labelling is done by society, judging the characteristics of the person against socially-accepted norms and values, and can lead to the individual labelling themselves as someone not meeting those norms and values (Crocker & Quinn 2000).

Individuals with IBD-fatigue felt unable to disclose the true reason for not always being able to take part in social events as they perceived that fatigue would not be a valid reason for not engaging socially. This led to self-exclusion or being excluded by others, and being seen as somehow different (Clow 2001). In an employment situation, individuals also feared that disclosing the fact that they were fatigued would be judged negatively by their employer and colleagues as not taking their job seriously, not managing their time effectively, and being less productive. They feared being overlooked for development and promotion opportunities. In instances where disclosure took place they felt reliant on the mercy of their employer.

Labelling, stereotyping, separation and emotional reactions, may lead to discrimination and loss of status (Link & Phelan 2001, Link *et al.* 2004). A fatigued individual who is unable to fulfil the roles as before, e.g. becoming an 'irresponsible parent', 'unreliable worker' or 'no fun to be with' may suffer negative outcomes such as marriage breakdown, being overlooked for promotion or excluded from social activities. It also impacts on the individual's cognitive and emotional reactions, their integrity of self and their social

identity. Negative perception of self, predisposes individuals to poor outcomes by threatening self-esteem, educational, professional and personal achievements, and mental or physical health (Link *et al.* 2004, Ottati *et al.* 2005).

10.3.2 Causes and management of fatigue

The findings from the present study and the two literature reviews on IBD-fatigue (Chapter 2), and cancer, RA and MS (Chapter 4), all report similar factors contributing to fatigue as well as many similar methods used in attempts to manage this symptom.

10.3.2.1 Factors aggravating fatigue

The primary factor contributing to fatigue across all conditions was always reported to be the condition itself (Repping-Wuts *et al.* 2008, Matcham *et al.* 2015). Factors exacerbating fatigue include immobility, depression, reduced physical activity, pain anxiety, disturbed sleep, poor nutrition and low quality of life (Glaus *et al.* 1996, Amato *et al.* 2001, Bakshi 2003, Hewlett *et al.* 2005, Randolph & Arnett 2005, Gupta *et al.* 2007, Mills & Young 2008, Repping-Wuts *et al.* 2008, So *et al.* 2009, Lerdal *et al.* 2011, Irwin *et al.* 2012, Acciarresi *et al.* 2014, Duncan *et al.* 2015). All factors could be grouped as physical (such as anaemia or disease activity), psychological (e.g. depression and quality of life) and situational (including unemployment, financial difficulties or social support) (Bager *et al.* 2012, Jelsness-Jørgensen *et al.* 2012b, Vogelaar *et al.* 2013, Cohen *et al.* 2014, Kappelman *et al.* 2014, Grimstad *et al.* 2015, Norton *et al.* 2015). Factors had either a direct or an indirect impact on fatigue for different individuals. The presence of multiple factors and the inter-relationship between physical, psychological and situational factors are likely to contribute to the severity of fatigue (Mitchell *et al.* 2005).

In IBD-fatigue, as well as in fatigue in other chronic conditions, the majority of information about the relationship between different factors and the severity of fatigue comes from cross-sectional studies. However, the direction of the causal relationship is impossible to establish from those studies (Glaus *et al.* 1996, Hewlett *et al.* 2005, Randolph & Arnett 2005, Repping-Wuts *et al.* 2008, van Langenberg & Gibson 2010, Czubor-Dochan *et al.* 2013a, van Langenberg & Gibson 2014). Disease activity is indisputably the strongest factor underlying IBD-fatigue (Minderhoud *et al.* 2007, Romberg-Camps *et al.* 2010, Graff *et al.* 2011). However, disease activity alone cannot explain the presence or severity of fatigue, as a significant proportion of patients who are in remission report fatigue (Minderhoud *et al.* 2003, Hauser *et al.* 2005, Romberg-Camps *et al.* 2010). In conditions

such as MS, with relapsing and remitting presentations, the evidence is also unclear how the variability of symptoms relate to the severity of fatigue (Randolph & Arnett 2005).

Fatigue has been reported as a cardinal symptom of anaemia across different conditions and the relationship between anaemia and fatigue has been extensively studied with conflicting results being reported. In IBD-fatigue, some studies report a link between low haemoglobin and fatigue (Simren *et al.* 2008, Graff *et al.* 2011, Jelsness-Jørgensen *et al.* 2011a, Jelsness-Jørgensen *et al.* 2011b) whilst others do not report such a relationship (Minderhoud *et al.* 2003, Goldenberg *et al.* 2013, Graff *et al.* 2013). Some studies report a link between anaemia and fatigue for either CD or UC patients. For example, Romberg-Camps *et al.* (2010) report a significant correlation between anaemia and fatigue for UC patients ($p=0.05$) but not significant for CD patients, as do Yoo *et al.* (2014) ($p=0.005$ for UC, and $p=0.826$ for CD patients) while Bager *et al.* (2012) report a positive correlation ($p=0.05$) for male CD patients only.

In other conditions, improvement of haemoglobin values to over 12g/dl led to patients reporting substantially greater improvements in energy, ability to perform usual activities and overall health ($p<0.0001$). However, whereas fatigue is often attributed to low haemoglobin levels, anaemia is not the only cause of fatigue in cancer patients, and the precise relationship between haemoglobin and fatigue is not well understood (Stone *et al.* 2000, Cella *et al.* 2004).

Quantitative studies in other conditions identify a strong interaction between fatigue, depression and emotional distress (Mohr *et al.* 2003, Armes *et al.* 2004, Fuller-Thomson & Sulman 2006, Mikocka-Walus *et al.* 2007, Fuller-Thomson & Nimigon 2008). This was confirmed by evidence from a systematic review of fatigue in cancer which showed a correlation of fatigue with depression and with anxiety. Studies report depression has significant correlation with fatigue ($p<0.01$) (Bakshi 2003, Siegert & Abernethy 2005, Kinsinger *et al.* 2010). Often, the direction of the relationship between factors is difficult to establish and this has been illustrated in numerous studies investigating fatigue and depression, with recommendations for longitudinal studies being made to better delineate directionality (Amato *et al.* 2001, Mohr *et al.* 2003, Randolph & Arnett 2005, Gupta *et al.* 2007, Brown & Kroenke 2009, So *et al.* 2009).

There is a relationship between depression, social isolation and social support. A study in MS patients showed a cycle of depression, leading to social isolation, which in turn leads

to a reduction in social support contributing to increased depression (Mohr *et al.* 2004). This cycle is also present in IBD-fatigue, where better social support leads to improvements in social functioning, and reductions in depression and fatigue (Hauser *et al.* 2005, Tanaka & Kazuma 2005).

The combination of multiple factors (physical, psychological, situational) have a different effect on each individual. The correlation between factors needs to be better understood and requires an assessment that is specific to each individual. The order in which these factors occur may be sequential for that individual, but more often it presents itself in a complex, tangled and web-like structure. In order to be able to help individuals manage the fatigue it is most likely that a combination of methods should be utilised.

10.3.2.2 Management of fatigue

Different IBD-fatigue management methods tried by participants were reported: physical, psychological, cognitive and situational, with further sub-categories within each. Most of these were ineffective or only had a short-term benefit in alleviating but not eliminating fatigue. This could be due to the paucity of evidence on the effectiveness of management methods in IBD-fatigue, including the time-period, combination or intensity of method to be used. The methods used by participants to manage fatigue were therefore experiential and not evidence-based. There have been a limited number of studies testing non-pharmacological and pharmacological and/or physical interventions in IBD-fatigue.

The evidence from the review of qualitative literature (Chapter 4) in relation to fatigue management in cancer, MS and RA identified the use of non-pharmacological, behavioural and educational interventions. Fatigue management methods used across these conditions include sleep, rest, energy conservation, psychological adjustments, practical changes, prioritisation as well as seeking and accepting support (Stuifbergen & Rogers 1997, Potter 2004, Jacobsen *et al.* 2007, Repping-Wuts *et al.* 2008, Nikolaus *et al.* 2010b, Tsai *et al.* 2010). All these methods were identified through qualitative studies, and as such, the effectiveness of the interventions was not established.

A few studies in IBD-fatigue tested non-pharmacological interventions in IBD-fatigue (Garcia-Vega & Fernandez-Rodriguez 2004) and solution-focused or problem-focused therapy (Vogelaar *et al.* 2011, Vogelaar *et al.* 2014). Whilst in Vogelaar *et al.*, short-term results were significant ($p < 0.001$), these studies did not provide long-lasting reductions in IBD-fatigue.

Systematic reviews and other studies report a range of interventions for managing fatigue across different chronic conditions (MS, cancer, RA, CFS, systemic lupus erythematosus). Many interventions have been reported to have a significant positive effect on reducing fatigue (Stricker *et al.* 2004, Rimes & Chalder 2005, McNeely *et al.* 2006, Neill *et al.* 2006, Armes *et al.* 2007, Kangas *et al.* 2008, Hewlett *et al.* 2011, Payne *et al.* 2012, Blikman *et al.* 2013). Furthermore, studies in cancer suggest that social support and the role of carers is vital in providing psychological support and reducing negative emotions of fatigue sufferers (Armes & Addington-Hall 2003). Among the tested interventions such as energy conservation, graded exercise therapy, CBT, and nutritional and physiological interventions, only CBT and graded exercise were consistently associated with statistically significant reductions of fatigue across different conditions (Stricker *et al.* 2004, Rimes & Chalder 2005, Neill *et al.* 2006, Hewlett *et al.* 2011, Blikman *et al.* 2013). A number of other interventions in chronic conditions, i.e. energy conservation, nutritional and physiological interventions, progressive muscle relaxation, education, anticipatory guidance, and screening for treatable risk factors and other co-morbidities are only likely to have a short-term effect in ameliorating fatigue (Newell *et al.* 2002, Rimes & Chalder 2005, Neill *et al.* 2006, Hewlett *et al.* 2011, Blikman *et al.* 2013, Cramp *et al.* 2013). There were a number of other studies reporting significant results on reducing fatigue. However, interventions were tested in a relatively small number of studies, often in uncontrolled or pilot studies (Rimes & Chalder 2005, Mitchell *et al.* 2007, Mitchell *et al.* 2014). This diversity of interventions and study designs, and the use of different instruments to assess fatigue do not readily allow comparison of study outcomes (Cairns & Hotopf 2005, Neill *et al.* 2006). In order to establish the effectiveness of interventions, it is important to compare their duration and frequency, optimal characteristics, and whether they are group or individual interventions, self-managed or interventions managed by the HCP (Cairns & Hotopf 2005).

The positive effect of exercise on individuals with IBD-fatigue was suggested in a recent randomised control study. This pilot study compared exercise advice (15 minutes consultation), omega-3 fatty acid supplementation (2970mg per day), dietary consultation and a placebo in reducing IBD-fatigue, and found that fatigue was significantly reduced in the exercise group ($p = 0.03$) (McNelly *et al.* 2015). Whilst this study of IBD-fatigue found that those taking omega-3 supplementation reported a significantly greater level of fatigue ($p = 0.02$), studies of fatigue in other chronic conditions, such as cancer reported that high

intake of omega-3 decreased inflammation and decreased physical aspects of fatigue (in cancer, $p < 0.05$) (Cerchiatti *et al.* 2007, Jouris *et al.* 2011, Alfano *et al.* 2012).

Individuals with IBD reported making dietary changes as part of controlling the symptoms and felt that dietary manipulation may be beneficial for them (Lindberg *et al.* 2014). Dietary changes related to avoidance of certain foods – as they believed that food played a role in disease relapse (Zallot *et al.* 2012, Cohen *et al.* 2013, Zallot & Peyrin-Biroulet 2013, Lindberg *et al.* 2014). Diet was also used as a behavioural factor to control and minimise their symptoms, including pain, diarrhoea and fatigue (Jamieson *et al.* 2007).

IBD-fatigue reduction was also reported in a number of studies testing pharmacological interventions. Of these, only one was specifically designed to test the reduction of fatigue (Costantini & Pala 2013). This involved the administration of thiamine, with doses dependent on bodyweight (600mg per day for 60kg to 1500mg per day for 90kg bodyweight). Ten of the 12 study participants showed complete regression and two near-complete regression of fatigue. However, the findings need to be seen within the study limitations, including small sample size, no control group or follow-up (Costantini & Pala 2013). The other studies, testing infliximab (Lichtenstein *et al.* 2002, Minderhoud *et al.* 2007) and adalimumab (Loftus *et al.* 2008) were related to the management of CD, with fatigue measured as a secondary outcome. High cost and serious side-effects make it unlikely that infliximab or adalimumab would be recommended for the treatment of IBD-fatigue.

In other chronic conditions a number of pharmacological interventions, such as melatonin, oral nicotinamide adenine dinucleotide and hydrogen (NADH), methylphenidate, antidepressants (fluoxetine and phenelzine), corticosteroids and selegiline were tested for managing fatigue (Rimes & Chalder 2005, Chambers *et al.* 2006, Mitchell *et al.* 2007). The only longer-term reduction of fatigue was reported from NADH, whilst corticosteroids led to a short-term improvement in fatigue with the benefit rapidly attenuating when treatment was discontinued, and inconclusive results found for the other tested agents (Rimes & Chalder 2005, Chambers *et al.* 2006, Mitchell *et al.* 2007).

In light of the multi-factorial causes of fatigue as discussed earlier (Section 10.3.2.1), and the evidence demonstrating the effectiveness of some interventions on reducing fatigue across different conditions, a Fatigue Management Model is proposed (see Figure 10-1). The Model incorporates the continuum of the severity of fatigue and its impact on an

individual's life. A step-wise (8 Steps) approach should be taken in the first cycle of the Model implementation, and 7 Steps thereafter, omitting the first step – identifying fatigue as problematic for an individual. The Model offers flexibility in terms of fatigue severity and accommodates differences in factors affecting fatigue and the effect that fatigue has on the individual's life, as well as the individual's responsiveness to the methods of fatigue management. The Model will offer a tool for HCPs to actively engage with the process of assessment and management of fatigue.

Studies of IBD-fatigue management identified no interventions with long-term effects on fatigue reduction. However, there is consistent evidence from studies in other chronic conditions that graded exercise and CBT do have a significant effect on reducing fatigue. In view of the many similarities in the dimensions of, and factors contributing to fatigue identified across different conditions including IBD, there is a strong indication that methods effective in managing fatigue in other conditions should be tested for effectiveness with the IBD population. Furthermore, there was a range of interventions from studies in chronic conditions reporting positive but inconsistent evidence on reducing fatigue. With further studies, the effectiveness may be proven and will add to the choice of interventions available to manage IBD-fatigue.

Employing complex interventions by simultaneously manipulating the range of factors (e.g. diet, sleep, activities, stress reduction) may produce a small improvement (marginal gain) in each factor, but lead to a substantial overall reduction of fatigue. The variety of factors affecting fatigue and the different ways that it impacts on the individual indicates that the methods used to manage fatigue should be appropriate to the individual's preference, capability and resources.

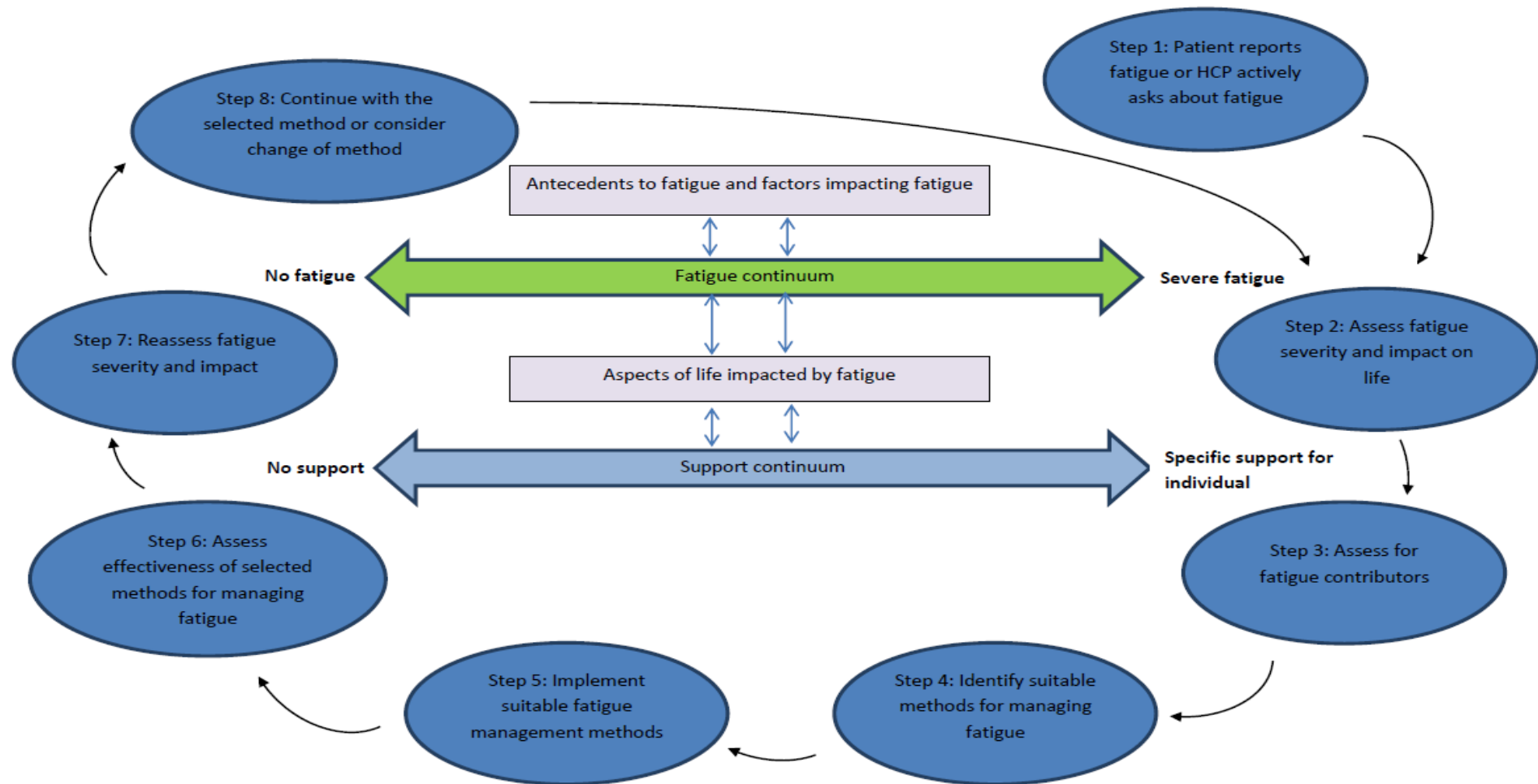


Figure 10-1 Fatigue management model

10.3.3 Living with fatigue

Living with fatigue is seen by individuals as debilitating and restricting. As a symptom of chronic conditions, fatigue has been shown to have predominately a negative impact on every aspect of an individual's life and is characterised in terms of deterioration and loss (Gignac *et al.* 2000, Flensner *et al.* 2003, Olson *et al.* 2007). Participants involved in the present IBD-study all talked about loss and restrictions to their lives as a result of fatigue. The study findings reported in Chapter 9 highlighted the negative impact of fatigue on an individual's life, loss of their previous life, and restriction of their life with fatigue, leading to negative feelings and low self-esteem. Every day was another battle with fatigue, trying to preserve a sense of normality.

10.3.3.1 How much have I lost

Experience of living with IBD-fatigue was characterised by a disparity between individuals' lives prior to, and following the onset of fatigue. This perceived loss occurred in physical, cognitive, emotional and social aspects of life and led to a feeling of loss, sadness and frustration, a sense of being 'old before time'. Individuals perceived fatigue as debilitating and as the main reason for their lives to deteriorate. Many were left with a sense of being of lesser value as a result of fatigue. They were constantly comparing their lives before fatigue with their lives as they are now. This comparison was always framed in a sense of what they could not currently do; a perceived loss in many aspects of their personal, social and professional lives, a sense of being stopped or limited in what they were able to do because of fatigue.

Fatigue has been reported in negative terms in studies across chronic conditions. In MS, this included limitations caused by the loss of physical energy (Flensner *et al.* 2003), as well as communication problems, an inability to find appropriate words and difficulties in pronunciation (Blaney & Lowe-Strong 2009), leading to loss of the former independent self and social life. In RA studies, fatigue was also shown to result in the loss of the independent self, with far-reaching effects on physical emotions, relationships and social and family roles (Hewlett *et al.* 2005), and a negative impact on daily life (Nikolaus *et al.* 2010b). In chronic heart failure, Hägglund *et al.* (2008) found that fatigue: the loss of physical energy and the presence of feebleness, led to loss of independence, while Jeon *et al.* (2010) showed that fatigue in this condition led to social isolation and the feeling of being abandoned or let down by family and friends. Studies of cancer-related fatigue found

difficulties in communication and finding appropriate words (Bennett *et al.* 2007), as well as limitations in physical and cognitive ability, low self-esteem, low motivation and difficulties in taking the initiative (Magnusson *et al.* 1999, Bennett *et al.* 2007).

Fatigue was perceived as the main reason for loss of identity and previous self by individuals with IBD, who at the same time considered IBD as the main cause of their fatigue. Fatigue in other chronic conditions, for example cancer, MS, RA and chronic heart failure, was also reported as the most debilitating and burdensome factor (over factors such as pain, nausea and diarrhoea), and the main reason for leading a restricted life, with the primary condition being seen as the main cause of fatigue (Flensner *et al.* 2003, Olson *et al.* 2007, Hägglund *et al.* 2008, Nikolaus *et al.* 2010b, Farrell 2013).

Fatigue related to chronic illness should be seen in conjunction with the impact of restrictions imposed by that illness. Chronic illness and fatigue have the same restricting impact on individuals, intensifying the negative effects (Porock & Juenger 2004, Olsson *et al.* 2005, Repping-Wuts *et al.* 2008). The individual leads a narrowed and restricted life, with an inability to do things they valued and enjoyed in the past. Fatigue is experienced through the loss of life before fatigue and is experienced by the individual through their weak and unreliable body and mind. A fear of not being able to fulfil certain roles leads to voluntary restrictions of life in order not to be seen as incompetent. The loss of the former self could be explained in the context of the values of western culture: work ethic, fulfilment of roles, independence, self-efficacy and contribution to society (Phillips 1990, Olson *et al.* 2007, Pongthavornkamol *et al.* 2012).

10.3.3.2 New fatigued me

The debilitating effects of chronic illness have been reported in literature as depriving individuals of their previous self, leading to a restricted existence (Charmaz 1983, Eakes *et al.* 1998, Gignac *et al.* 2000, Jeon *et al.* 2010, McCombie *et al.* 2013). Individuals with IBD-fatigue presented predominately negative coping strategies. In exploring life with fatigue in IBD and its meaning, this part of the discussion analyses fatigue in primary chronic conditions where fatigue is reported as a symptom.

The loss of the former independent self, due to chronic illness and fatigue, requires the creation of a new and different self. This new self, offered by chronic fatigue and illness, is one of restriction, loss of control, social isolation and dependence on others.

Different adaptation models of living with fatigue have been proposed in the literature (Charmaz 1995, Livneh & Antonak 2005). The model proposed by Charmaz (1995) identifies three major strategies: experiencing and defining impairment; making bodily assessments and subsequently identity trade-offs; and accepting the sick role by allowing the illness to take over (Charmaz 1995). Livneh & Antonal (2005) refer to a number of psychosocial responses and coping strategies to chronic illness and disability. The possible responses include shock, anxiety, denial, depression, anger, hostility and adjustment. Coping strategies are stated as disengagement and engagement strategies. Disengagement includes passive, indirect or avoidance-oriented activities and is often associated with negative emotions and a lack of acceptance of, and adaptation to the chronic condition. Active, goal-oriented engagement strategies include information seeking, problem-solving, planning, and asking for, and accepting social support (Livneh & Antonal 2005). This style of coping is more likely to lead to better outcomes, higher levels of well-being, acceptance of condition, and successful adaptation.

Individuals with IBD-fatigue were constantly experiencing anxiety, negative self-image, low self-esteem and withdrawal from social situations, indicating a negative adaptation to the condition. In instances where attempts were made to adapt in a positive way, and to seek information and advice from HCP, individuals' complaints were questioned and disbelieved, they were informed that fatigue did not occur when IBD was in remission, and in cases where there was a relapse of IBD, gastro-intestinal symptoms were seen as a priority over fatigue.

The fluctuating and invisible nature of fatigue often created doubts among family and friends of the authenticity of fatigue and severity of its impact. Even if help and support was offered, a full understanding of the condition was often lacking, resulting in impatience and expectation of a quicker recovery and return to former roles. In instances where family and friends were supportive and offered help, individuals with IBD fatigue resisted accepting that support so as not to become dependent and burdensome.

At times, individuals did try positive coping such as sleep and rest, or prioritisation; however they were unsure how long to continue with these activities to experience a positive effect.

Examples of negative adaptations were reported in fatigue in other chronic conditions. These included a negative frame of mind, loss of self, low self-esteem, a loss of independent

life, a lack of participation in everyday activities, frustration, depression and anger. However, the incidence and severity of fatigue may not solely depend on the disease or treatment, but may depend to a considerable extent on the individual concerned and their responses (Glaus *et al* 1989, Flensner *et al* 2003, Livneh & Antonal 2005, Olsson *et al* 2005, Wu & McSweeney 2007, Nikolaus *et al* 2010). At the same time, studies in cancer, MS and RA showed a number of positive ways of coping with fatigue. Individuals were more willing to accept fatigue, as their primary conditions were socially acceptable and they were able to talk about them and seek support. They were often advised that fatigue was a part of the condition and a possible side-effect of their treatment. Individuals perceived fatigue as a process of the body being repaired, creating an anticipation of cure. Their complaints of fatigue were validated and linked to a specific cause, and as with cancer, where fatigue was linked with chemotherapy or radiotherapy, there was an expected end-point of fatigue coinciding with the completion of the treatment and hopefully cure (Potter 2004, Siegel *et al* 2012, Spichiger *et al* 2012).

For chronic conditions with remitting and relapsing presentation (such as IBD), and constantly shifting perspectives: with illness or wellness continually in the foreground of an individual's perspective, adapting to life with fatigue is not a linear process requiring a single decision (Charmaz 1995, Paterson 2001). The constant fluctuation of the symptom of fatigue requires constant changes and a continuous process of decision-making and re-negotiation. Individuals with IBD-fatigue may not be able to devote the energy to make those multiple decisions and continual re-adaptations. The result is a constant battle against, rather than the management of fatigue.

For individuals with IBD-fatigue, 'normal', pre-fatigue life is no longer possible, those who try to preserve their pre-fatigue lives go through a constant everyday battle, a battle that often ends in defeat, frustration and a crumbling-away of self-image. In the absence of the old, pre-fatigued self, a new self-image needs to be constructed, and a new life created (Lazarus *et al.* 1985, Charmaz 1995, Fournier *et al.* 2002, Anderson & Funnell 2005, Aujoulat *et al.* 2007, Livneh 2015).

10.4 Critique of the methodology and methods used and trustworthiness of the study results

Descriptive phenomenology, a research methodology which aims to reveal peoples' experience was selected to examine fatigue as experienced by individuals with IBD. Providing a better description of the phenomenon of fatigue helps with the progression of knowledge generation in this important, but grossly under-researched topic. This description is only achievable by utilising a qualitative study design (Creswell & Plano Clark 2007, Cope 2014). For the research findings to be accepted as valid and utilised by others, the study has to demonstrate trustworthiness and good quality. This could be assessed by examining the four components of trustworthiness: credibility, dependability, confirmability and transferability (Holloway & Wheeler 2002, Rolfe 2006). Various methodologies within the qualitative paradigm were considered, as presented in Chapter 5.

Descriptive phenomenology was selected in view of its aim of describing and developing a detailed understanding of the nature and meaning of everyday life – a life with fatigue. It was thus especially effective in studying the complexity of experiences and perceptions of fatigue from the individual's perspectives, to challenge conventional assumptions and meanings. Of the three key components of descriptive phenomenology, essences, intentionality and phenomenological reduction (Husserl 1970, Koch 1995, McLaughlin Gray 1997, Norlyk & Harder 2010), only phenomenological reduction, also known as bracketing, presented a real challenge in its execution. This challenge was both philosophical and practical, whether it is metaphysically possible to suspend prior knowledge to be fully objective in studying a subjective phenomenon (Sandelowski 1993, Barbour 2001, Bradbury-Jones 2007). This PhD research therefore incorporated bracketing as a 'sincere effort' to *reduce*, rather than *eliminate* bias (Ahern 1999). Bracketing was undertaken by looking at the experience of the individual person in order to get a better understanding of their experience. This led to the creation of themes and sub-themes where grouping of information perceived as the same category were put together. In a structural analysis, the bracket was widened in order to analyse and validate the results of the IBD study against the wider literature. Phenomenology as a methodology underpinned by philosophy could be interpreted as more flexible and open to researcher interpretation. A view frequently challenged by pure phenomenologists (Knafl 1994, Paley 1997, LeVasseur 2003, Paley 2005, Smith 2008). Some of the language created by Husserl, despite its challenges, also possesses distinct strengths. The 'vague' language of phenomenology allows for a range of interpretations and applications in various areas of practice and would

support the use of phenomenology for this research (Spiegelberg 1960, Cohen & Omery 1994, Barroso *et al.* 2003).

To achieve credibility of the findings, the most appropriate methods for study design should be employed. There are no clear guidelines on sample size in phenomenological research and a pragmatic decision has to be taken when to stop (Baker *et al.* 2012). A sample of twenty unstructured in-depth interviews was considered sufficient for this study and despite the costs, this was seen as the most appropriate way of capturing the breadth and depth of fatigue experience (Fontana & Frey 1994, Green & Thorogood 2014). The unstructured nature of the interviews gave scope to participants to speak about areas of interest to them, with the researcher being aware of the need not to ask leading questions (Legard *et al.* 2003, Silverman 2013).

Whilst the researcher started with the topic of IBD-fatigue in an attempt to identify and reveal its essences and meaning, the detailed description of the essences of the experience and the order in which they were talked about were left to participants. Attentive listening helped the researcher to focus on the topic raised by the participant and to ask further clarifying or expanding questions. A non-judgemental attitude helped participants to feel accepted and stimulated further conversation. Given the embarrassing nature of IBD and the participants' low levels of energy due to fatigue, the researcher created a sense of comfort, safety and control, leading to better rapport with the participants' and this had a positive impact on the flow of conversation, heightening the feeling of trust (Fontana & Frey 1994, Fontana & Frey 2000, Wimpenny & Gass 2000).

The use of Moustakas' method (1994) to analyse data created a number of challenges with a long and convoluted process and the use of 'over-complicated' language. Whilst the process is very time-consuming, it permits prolonged engagement with the data and hopefully results in enhanced credibility. Moustakas method recommends that all vague, overlapping and repetitive phrases should be eliminated at the second step (of eight), however in light of the possibility of new horizons and meanings being discovered, no data were deleted or excluded from the analysis at this early stage. This contributed to a 'richer' description of the phenomenon, and appeared to be a more rigorous and systematic approach to the data analysis.

In order to maintain the insider perspective and to be trustworthy in providing credible study results, the researcher used reflexivity, keeping a reflective journal throughout the

whole research process. It could be argued that self-awareness and self-reflection, required in the process of phenomenological reduction, helps in the reduction of bias (Braun & Clarke 2013). However, achieving rigour is more difficult to attain than simply checking the set of criteria and it is impossible to categorically state that there was no subjective researcher influences that may have affected the process and consequently the findings of the study.

10.5 Study limitations

In qualitative research some study characteristics can be perceived as both a weakness as well as a strength. Some characteristics of qualitative study design e.g. small sample size, non-generalisable findings, are reported in literature as limitation as a result of quantitative framework being used to assess the study quality (Lincoln *et al.* 2011). To achieve the depth of the data and the detail description of the studied phenomenon, the sample size was deliberately small (Baker *et al.* 2012). Additionally, the population sample was intentionally heterogeneous, allowing for a greater variety of fatigue experiences to be captured and reported. The study at no point aimed to produce generalisable findings representative of the entire UK IBD population reporting fatigue.

Despite the aims on the study being achieved, the study findings should be considered in light of a number of limitations. Only members of Crohn's and Colitis UK charity were eligible to participate in this study and were recruited via an advertisement in the Crohn's and Colitis Newsletter. The first stage of recruitment may have attracted highly committed self-selected volunteers, leading to selection bias with a subsequent impact on the data collected (Green & Thorogood 2014). Selecting only members of the Charity may have precluded participants from certain social and economic groups (e.g. no access to internet or no disposable income to pay annual membership) and those who may have been less proactive.

The study sought to recruit participants diagnosed with IBD and reporting fatigue. In the study findings, only a limited number of effective methods of managing fatigue were identified. This may have been the result of a specific selection criterion which sought to recruit individuals with IBD-fatigue, thus excluding those who possibly had more effective fatigue-management strategies. Those who managed fatigue more effectively may have

excluded themselves from the study or were not selected if only a low level of fatigue was reported.

The use of single interviews precluded follow-ups to seek subsequent explanation and clarification of any issues if required. Employment of multiple interviews may have resulted in greater clarity of some of the descriptions and experience of fatigue.

As this was a PhD study which has to be undertaken independently by a solo researcher and being a novice researcher may have affected the quality of the research and its outcomes. This limitation was partially overcome by regular meetings and discussions with the study supervisors.

10.6 Recommendations from the study

Fatigue has been presented as a complex, multifactorial and multifaceted symptom that impacts on all aspects of an individual's life. People affected by IBD-fatigue reported a lack of its understanding and awareness of effective methods to manage fatigue. They also reported a varied level of understanding and support from healthcare professionals. In light of the study outcomes and review of the wider literature on fatigue in IBD and other chronic conditions, there are several recommendations for further research, practice and education.

10.6.1 Recommendations for further research

This study has been the first, in-depth exploration of fatigue in IBD, and as such, provides a valuable contribution to knowledge and understanding of this symptom. The findings of the study have already been presented at national and international forums with further dissemination planned (Appendix XXIV). In order to have a strong evidence base to benefit both patients and practitioners, further research across different paradigms (qualitative, quantitative and mixed methods) is required. Therefore, the following recommendations for future research have been made:

- i. **Further exploration of the phenomenon of IBD-fatigue to confirm and/or elaborate on its description and understanding.** Studies with homogenous and heterogeneous groups of participants' characteristics, such as: age, gender, length of time since diagnosis, different stages of IBD (remission or relapse), personal

circumstances, and support systems may provide better explanation of the role different factors play, and the relationship between the factors.

- ii. **There is a need for further research to fully understand fatigue in IBD.** Longitudinal qualitative studies could be applied to assist the understanding of the complexity of IBD-fatigue, reflecting changes of fatigue and its severity over time at different points following diagnosis.
- iii. **Further exploration of language used to describe fatigue and its meaning.** This study identified that participants used different terms describing fatigue interchangeably. Differences between the concepts of fatigue, tiredness and exhaustion, and their meaning needs further exploration via qualitative and mixed methods studies.
- iv. **Cause and effect relationship between fatigue and other risk factors, such as, anxiety, stress, depression, disease activity, pain, sleep, need to be investigated.** Employing quantitative study designs will provide a better opportunity to explore the correlation between different factors.
- v. **Exploration of possibility of fatigue reduction by multi-symptom management of IBD and involvement of multidisciplinary team in patient care.** Most participants reported presence of more than one symptom, both in remission and in relapse, which impact on physical, psychological, cognitive and social functioning and a greater level of fatigue. Holistic and multi-agency approach to care provision in IBD is warranted.
- vi. **Determine the relationship between individual's level of knowledge about IBD and IBD-fatigue, and the level of reported fatigue.** In this study some participants were poorly informed about the causes and trajectory of IBD, and some were unaware that fatigue may be one of IBD symptoms. This appeared to cause more health-related distress and may have impacted on negative coping strategies.
- vii. **Exploration of effective coping strategies and factors influencing adaptation.** Identification of factors contributing to either positive or negative coping (for example, psychological profiling or identifying support systems required), may help in selecting person-specific advice and support for living with fatigue and its long-term impact.
- viii. **Further research in fatigued and non-fatigued group of participants.** To identify different fatigue management methods and differences of coping and perceiving their illness.

- ix. **Exploration of impact of fatigue on family unit.** A broader impact of fatigue not just on the individual diagnosed with IBD, but on the family unit as a whole needs to be investigated. This may lead to development of interventions specific to supporting the whole family.
- x. **Development and testing of interventions to manage fatigue is urgently needed.** Interventions (pharmacological and non-pharmacological) to manage fatigue need to be developed simultaneously, if physical and mental aspects of fatigue are to be managed effectively.
- xi. **Exploration of fatigue in groups with various chronic conditions.** This study identified various similarities and differences in fatigue and its meaning between populations with different chronic conditions. Exploring the symptom of fatigue in different conditions may lead to discovery of its aetiology and possible management methods across different conditions.

10.6.2 Recommendations for clinical practice and education

Transferability of study findings is not the primary aim and most results in qualitative research only apply to the study participants (Lincoln *et al* 2011). Nevertheless, in light of multiple possibilities of fatigue description and multiple horizons of its experience it is possible the complex nature of fatigue requires intricate strategies for its assessment and management. Additionally, the chronic nature of IBD requires the individual to adapt to the long-term impact that the condition has on their personal and professional life. The IBD Standard Group (2013) stated that IBD patients should receive individualised care, timely advice for their physical and psychological needs, and access to specialist care, such as gastroenterologists, IBD nurses, pharmacists, dietitians and psychologists. The study results indicate that there are considerable variations in terms of professionals' knowledge, quality of care and support provided to patients. Not all hospitals employ professionals from all the different professional groups, and therefore do not provide access to the optimal patient care. With this in mind, the following recommendations for practice and education have been made:

- i. Fatigue affects physical and psychological well-being of individuals diagnosed with IBD, therefore multidisciplinary group members have an important and varied role to play in providing holistic care and support to newly-diagnosed as well as people living with long-term effects of IBD and fatigue.

- ii. Routine care for people with IBD should include advice on fatigue at the point of diagnosis and at regular points during the follow up out-patient clinic consultations.
- iii. Participants' awareness of fatigue as one of the symptoms of IBD varied and they lacked information on fatigue and its management. HCPs should provide patients with regular information regarding fatigue and its management, so patients can become more self-sufficient in managing the symptom and actively seeking help as and when required.
- iv. Participants' attempts of reporting fatigue and seeking advice were predominantly met with lack of understanding at best, and ignorance and dismissal at worst from HCPs. HCPs need to recognise and accept that fatigue is frequently experienced by people with IBD, both in remission and in active disease. HCPs have an important role to play in providing support and information to people with IBD and fatigue.
- v. HCPs should be proactive in assessing fatigue. A systematic assessment of fatigue should be incorporated into the standard IBD care. Over the past few years more studies were conducted specifically into IBD-fatigue. HCPs need to incorporate the newly available evidence based information into their daily patient care.
- vi. HCPs should create an opportunity and allocate time to ask people about their fatigue level and to have a meaningful conversation regarding fatigue assessment and management.
- vii. HCPs need a better awareness and education regarding fatigue, so they will be better prepared to provide help and support required by people with IBD and fatigue.
- viii. General public, family and friends of people diagnosed with IBD and fatigue need to be better informed about the nature of the illness, the symptoms and possible wider impact on people's lives and support required.
- ix. Participants also identified need for their employers and colleagues to be better informed about IBD and fatigue, so they can be better understood and the right support is available in the work environment.

In order to provide recommendations for change of policy in IBD care services further research and more extended empirical findings are required.

10.7 Conclusion

Fatigue is a major and debilitating symptom for individuals diagnosed with IBD. Participants' experience of fatigue varied greatly, depending on their process of being diagnosed with IBD, trajectory and severity of their illness and severity of their fatigue. Various terms used to describe fatigue only confirm its complicated nature that is perplexing, difficult to comprehend and explain even by the person experiencing it. This is compounded by its invisibility which makes the existence of the symptom be questioned by others.

Multiple factors were identified as contributing to fatigue and its severity, with a range of impacts, both direct and indirect, on participants' lives. Not all factors had the same impact on participants and their ability to cope with fatigue. Individual variations of the experience of fatigue derived from this present study, as well as from a wider literature, suggest that personal characteristics, support systems and the individual's ability to cope with challenging and stressful situations and process of adaptation to this chronic condition need to be further explored.

This is the first qualitative study to present an in-depth exploration of IBD-fatigue and its impact on individuals' lives. The study provides a new and valuable insight into IBD-fatigue and contributes to its better understanding. Fatigue is invisible and subjective, but is very real and multifaceted with variations in intensity. It is unpredictable and has a restricting and disabling impact on individuals' lives.

The array of factors contributing to fatigue appear to be inextricably linked, resulting in different, but substantial negative effects on individuals' lives. Studying multiple factors simultaneously may provide a fuller understanding of the diverse horizons of fatigue. Individuals should be informed that fatigue is one of the symptoms of IBD. This knowledge may enable them to report fatigue sooner and to seek support and advice from HCPs. Fatigue should therefore be assessed on a regular basis and information specific to the individual should be provided regarding strategies for managing it.

This thesis allowed for the main concepts of descriptive phenomenology to be explored and critically analysed. The rationale for choosing descriptive phenomenology as the most suitable method for achieving the study aims was also provided. These relate primarily to a close match between the aims of the study, namely gaining an insight into people's experience from their own perspective, the values and meanings people ascribe to their own

experience and the characteristics of phenomenology, that is to describe the texture and structure of people's lived experience.

This study provides insight into the experience of fatigue in people with IBD and may help with the progression of knowledge in this debilitating but under-researched symptom. The study also identified positive and negative coping strategies; however there is insufficient evidence to explain the differences in coping with fatigue. The findings from this study merit further, longitudinal studies in the area of the impact of fatigue on people's lives and developing and testing interventions for fatigue management.

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List of Appendices

Appendix I Output from the IBD-fatigue research programme

	AP&T Alimentary Pharmacology and Therapeutics
Review article: description and management of fatigue in inflammatory bowel disease	
W. Czuber-Dochan*, E. Ream* & C. Norton*†	
<p>*King's College London, Florence Nightingale School of Nursing & Midwifery, London, UK. †Imperial College Healthcare NHS Trust, London, UK.</p>	SUMMARY
<p>Correspondence to: W. Czuber-Dochan, King's College London, Florence Nightingale School of Nursing & Midwifery, James Clerk Maxwell Building, 57 Waterloo Road, London SE1 8WA, UK. E-mail: wladzia.czuber-dochan@kcl.ac.uk</p>	<p>Background Fatigue is a common and leading concern for patients with inflammatory bowel disease (IBD). It is managed inadequately in IBD, and there is little evidence to support interventions.</p>
<p>Publication data Submitted 29 October 2012 First decision 30 November 2012 Resubmitted 17 December 2012 Accepted 18 December 2012 EV Pub Online 13 January 2013</p>	<p>Aim To examine patients' experience of and factors contributing to IBD-fatigue, and to appraise its management by patients and healthcare professionals.</p>
<p><i>This uncommissioned review article was subject to full peer-review.</i></p>	<p>Methods Seven electronic databases were searched. Subject headings and free-text searching were used, with no time limit set. Reference lists of retrieved papers were searched manually.</p>
<p>Results Twenty-eight papers were reviewed. Researchers used terms including 'fatigue', 'low energy', 'tiredness', 'decline in vitality and vigour' and 'reduced energy and vitality'. Different definitions were used to conceptualise fatigue. None of the reviewed studies asked patients to describe the experience of fatigue in their own words. Numerous physical, psychological and situational factors associated with fatigue were identified. Three small randomised control trials reported a favourable effect of infliximab and adalimumab on fatigue. One intervention study reported benefit from a stress management programme and one from solution-focused therapy.</p>	
<p>Conclusions Inconsistent use of terminology, lack of data from patients' perspective on inflammatory bowel disease-fatigue and lack of evidence to support its management contribute to fatigue being largely ignored or overlooked by healthcare professionals. Future research should explore the experience of IBD-fatigue from the individual patient perspective. Further studies are required to fully explore the factors associated with fatigue and to develop patient-centred interventions to reduce fatigue.</p>	
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<p>© 2013 Blackwell Publishing Ltd doi:10.1111/apt.12205</p>	<p>505</p>

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ORIGINAL RESEARCH

The experience of fatigue in people with inflammatory bowel disease: an exploratory study

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CZUBER-DOCHAN W., DIBLEY L.B., TERRY H., REAM E. & NORTON C.
(2013) The experience of fatigue in people with inflammatory bowel disease: an
exploratory study. *Journal of Advanced Nursing* 69(9), 1987–1999. doi: 10.1111/
jan.12060

Abstract

Aims. To explore fatigue, the impact it has on daily life and the strategies used to ameliorate the symptom, as described by people with inflammatory bowel disease.

Background. Fatigue is the most troublesome symptom during remission of inflammatory bowel disease. Fatigue affects people's daily functioning, impacting on quality of life. There is limited understanding of the nature of and the ways fatigue in inflammatory bowel disease is experienced and managed in everyday adult life.

Design. An epistemological interpretive approach to understand participants' self-reported experiences of disease-related fatigue.

Methods. A convenience sample of 46 participants was recruited from the Crohn's and Colitis UK member database. Five focus group interviews (November 2008–February 2009) were conducted, audio-recorded, transcribed, and analysed using an inductive thematic framework.

Findings. Five themes were identified: the experience of fatigue, causes of fatigue, managing fatigue, consequences of fatigue, and seeking support. Fatigue had a debilitating effect on the social and emotional well-being of participants and limited their employment opportunities. People used a range of strategies to cope and reported that fatigue-related issues seemed to be poorly understood by clinicians and were not addressed in medical consultations.

Conclusion. Fatigue was an inextricable part of daily life for some people with inflammatory bowel disease. Specialist nurses and medical colleagues need to address the personal, social, and economic consequences of fatigue, whilst further nursing research would improve understanding of the impact of fatigue and help develop appropriate intervention strategies for people with inflammatory bowel disease.

Keywords: fatigue, inflammatory bowel disease, nursing, specialist nurses



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Exercise in Individuals With Inflammatory Bowel Disease

ABSTRACT

There is increasing evidence that exercise may improve symptoms in individuals with inflammatory bowel disease (IBD). This study aims to explore issues that clinicians may need to consider when giving advice on exercise to such individuals. Limited existing evidence suggests that low to moderate physical activity may improve symptoms without any adverse effects in individuals with IBD. This is largely supported by the findings of the current case series of "exercising" individuals with IBD who reported that low- to moderate-intensity exercise (most commonly walking) had a positive effect on their mood, fatigue, weight maintenance, and osteoporosis. Overexertion was reported as a potential problem. Scant advice regarding exercise had been given by their healthcare professionals according to participants. The current literature and findings of this small case series suggest that exercise is likely to be beneficial and safe for individuals with IBD. However, more research is required on which recommendations for exercise could be based.

There is some supportive evidence that exercise is beneficial for individuals with inflammatory bowel disease (IBD) (Martin, 2011). However, people with IBD experience considerable barriers to exercise, including the unpredict-

able fluctuating nature of the disease and its symptoms such as pain, fatigue, and fear of fecal incontinence. There are currently no evidence-based guidelines for this group of patients that take such factors into consideration. Development of a practical physical activity protocol that can be recommended in routine clinical practice is a research priority (Chey & Rai, 2011). This article, by means of a literature review supplemented with qualitative data from a small case series, aims to explore the issues to be considered by clinicians when advising patients with IBD to increase exercise.

Methods

Literature Review

A selective review of evidence on exercise for IBD up to November 2011 (MEDLINE, EMBASE, CINAHL, and Cochrane data bases) was initiated. The search for articles on IBD was based on the search strategy used by the National Health Service (2011) evidence gastroenterology and liver disease specialist project team for the annual evidence update on IBD. This was combined for exercise using the following search terms: "exercise," "exercise therapy," and "exercise tolerance."

Case Series

Participants were a sample of convenience who were interviewed during pilot work for a larger study

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The authors declare no conflict of interest.

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Healthcare professionals' perceptions of fatigue experienced by people with IBD[☆]



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KEYWORDS

Inflammatory bowel disease;
Fatigue;
Healthcare professionals;
Phenomenological study

Abstract

Background and aims: Fatigue is one of the top complaints of people with inflammatory bowel disease (IBD); however this is often not addressed in clinical consultations. This study aimed to gain an understanding of healthcare practitioners' (HCPs) perception of IBD fatigue as experienced by people with IBD.

Methods: Descriptive phenomenology was conducted with 20 HCPs who work with people with IBD. In-depth semi-structured interviews were audio recorded and transcribed verbatim. Colaizzi's framework was used to analyse data.

Results: Three themes and several sub-themes were identified. The main themes were: the phenomenon of fatigue as perceived by HCPs; the impact of fatigue on patients' lives; and the methods used by HCPs to deal with fatigue. Fatigue was identified as an important, but difficult and frustrating, symptom to understand. HCPs reported that fatigue impacts on the emotional, private and public aspects of patients' functioning, however there were few methods suggested on how to assess and manage the fatigue. Many expressed frustration at not being able to help more. **Conclusions:** The study identified a gap in HCPs' knowledge and their understanding of the complexity of IBD fatigue and the full impact that IBD fatigue has on people's lives. There is a need for more research-generated evidence to enhance our understanding of the concept and the factors associated with IBD fatigue. Advances in the assessment and management of this complicated and poorly understood clinical symptom are needed in order to help enable HCPs to provide better quality care to people affected by IBD and IBD fatigue.

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Development and psychometric testing of inflammatory bowel disease fatigue (IBD-F) patient self-assessment scale



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KEYWORDS

Inflammatory bowel disease;
Fatigue;
Self-assessment questionnaire;
Psychometric properties

Abstract

Background and aims: Fatigue is one of the main symptoms of inflammatory bowel disease (IBD) and is frequently reported by people in both active and quiescent disease. Many different fatigue assessment scales have been used to measure fatigue, but none has been developed or tested in IBD. This study aimed to develop a fatigue scale specific to the needs and experiences of people with IBD.

Methods: A five-step sequential mixed method design was used: a qualitative phase to assess patients' experience of fatigue and its impact on their lives, and four mixed qualitative–quantitative phases to refine the scale and to assess its psychometric properties.

Results: 567 people participated in five phases. The resulting questionnaire has 3 sections: 5 questions assessing frequency and severity of fatigue; 30 questions rating the experience and impact of fatigue; and a free-text section asking for patients' comments and additional issues related to fatigue. Initial validation suggests that the questionnaire has good face and content validity, acceptable to excellent test–retest stability (ICC 0.74 for Section 1 and 0.83 for Section 2) and a high degree of internal consistency (Cronbach's alpha > 0.9).

Conclusions: Participants in the study confirmed that fatigue in IBD is burdensome. Items generated and refined by people with IBD-fatigue reflect their experience and form the basis of

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Assessing fatigue in patients with inflammatory bowel disease

Abstract

Fatigue in inflammatory bowel disease (IBD) has been reported to be a major issue in terms of its understanding, assessment, and management, for both patients and clinicians. This paper summarises the results of three separate but interlinked studies reporting on: health-care practitioners' perceptions of fatigue in IBD patients, an IBD fatigue patient self-assessment scale, and a checklist to assess the possible reversible factors contributing to fatigue. Health-care practitioners reported a lack of understanding of fatigue and a need for more information and education to help them to address fatigue in a constructive manner in clinical consultations. The IBD fatigue patient self-assessment questionnaire is a helpful tool to assess fatigue in a systematic manner, and provides a quantifiable score of the level of fatigue experienced by an individual. The screening checklist for IBD fatigue provides a valuable tool to identify the priorities for testing for clinically potentially reversible causes of fatigue.

Fatigue is a very common complaint made by people with inflammatory bowel disease (IBD), with some 40%–48% of patients in remission and 86% in active condition reporting the fatigue (Minderhoud et al, 2003; 2007; Romberg-Camps et al, 2010; Graff et al, 2011; Bager et al, 2012). Even higher figures of fatigue have been reported by the European Federation of Crohn's and Ulcerative Colitis Associations (ECCA) from their recent online survey, with 96% of patients feeling tired, weak, and worn out during a flare-up. This figure only reduces to 83% during remission (Wilson et al, 2012). However, patients report that health professionals do not take symptoms of fatigue seriously and that their complaints of fatigue are often not addressed in clinical consultations (Czuber-Dochan et al, 2013a). In a survey of health professionals' knowledge and awareness of IBD fatigue, the overwhelming majority (86%) self-rated their knowledge to be poor or fair, with only 14% assessing their knowledge as good or excellent (Crohn's and Colitis UK, 2014).

The symptom of fatigue has been described in literature as multidimensional, distressing,

and unpleasant, and it substantially affects people's quality of life (Minderhoud et al, 2003; van Langenberg and Gibson, 2010; Jelsness-Jørgensen et al, 2011). Owing to its subjective nature, fatigue has not received as much attention in research and clinical practice as some of the other intestine-related symptoms with a more physical presentation such as diarrhoea, bleeding, inflammation, or even pain (van Langenberg and Gibson, 2010).

At present, there is no consensus on best practice for the assessment or treatment of fatigue in IBD. The evidence base regarding the causes and management of IBD fatigue is weak (van Langenberg and Gibson, 2010; Czuber-Dochan et al, 2013b). A variety of mechanisms for fatigue have been investigated, but to date, there is insufficient evidence to support a specific theory on its pathogenesis (Minderhoud et al, 2003; 2007). While several causes of fatigue have been identified in previous studies (e.g. active inflammation, anaemia, stress, and sleep deprivation), there is also much contradictory evidence in relation to the factors correlated with fatigue (e.g. gender, age, anxiety, and

Key words

- Inflammatory bowel disease
- Fatigue
- Self-assessment
- Blood tests
- Assessment checklist

This article has been subject to double-blind peer review

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Assessing fatigue in inflammatory bowel disease: comparison of three fatigue scales

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SUMMARY

Background

Fatigue is commonly reported by patients with inflammatory bowel disease (IBD), both in quiescent and active disease. Few fatigue scales have been tested in IBD.

Aim

To assess three fatigue assessment scales in IBD and to determine correlates of fatigue.

Methods

Potential participants ($n = 2131$) were randomly selected from an IBD organisation's members' database; 605 volunteered and were posted three fatigue scales: Inflammatory Bowel Disease Fatigue scale, Multidimensional Fatigue Inventory and Multidimensional Assessment Fatigue scale and questionnaires assessing anxiety, depression, quality of life (QoL) and IBD activity. The questionnaires were tested for stability over time with another group ($n = 70$) of invited participants. Internal consistency was measured by Cronbach's alpha and test-retest reliability by the intraclass correlation coefficient (ICC).

Results

Four hundred and sixty-five of 605 (77%) questionnaires were returned; of 70 invited, 48/70 returned test (68.6%) and 41/70 (58.6%) returned retest. The three scales are highly correlated ($P < 0.001$). Test-retest suggests reasonable agreement with ICC values between 0.65 and 0.84. Lower age, female gender, IBD diagnosis, anxiety, depression and QoL were associated with fatigue ($P < 0.001$) on univariable analysis. However, on multivariable analysis only depression and low QoL were consistently associated with fatigue, while female gender was associated on most scales. IBD diagnosis, age and other factors were not consistently associated with severity or impact of fatigue once other variables were controlled for.

Conclusions

All three fatigue scales are likely to measure IBD fatigue adequately. Responsiveness to change has not been tested. Depression, poorer QoL and probably female gender are the major associations of fatigue in IBD.

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INFLAMMATORY BOWEL DISEASE AND FATIGUE: THE EFFECT OF PHYSICAL ACTIVITY AND/OR OMEGA 3 SUPPLEMENTATION

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Introduction: Fatigue is frequently reported by patients with Inflammatory Bowel Disease (IBD), despite disease remission. However, no previous intervention trial has studied this symptom. We tested the effects on fatigue in IBD patients from (i) individual advice to increase physical activity (PA) and/or (ii) supplementation with omega-3 fatty acids.

Method: Design: a randomised controlled 2x2 factorial study compared change-from-baseline scores in intervention and control groups. Primary outcome: change in FACIT-F (Functional Assessment of Chronic Illness Therapy - Fatigue) score; main secondary outcomes: change in fatigue survey scores including IBD-fatigue (IBD-F); PA by monitors (Actigraph, Pensacola, US); adverse effects. Eligibility: IBD remission; ≤ 2 portions oily fish/week; ≤ 60 minutes moderate-vigorous PA/week; no comorbidities causing fatigue; no depression. Interventions: exercise advice (15 minute consultation) and fish oil supplement (2.97g per day omega-3, "Take Omega 3"©, Edinburgh, UK); Controls: dietary consultation and placebo supplement. All patients received follow-up support (email, telephone).

Results: Over 640 IBD outpatients were screened: 74 of those eligible consented to inclusion and randomisation, 60 commenced the intervention, and 52 completed the study according to protocol. At baseline the four groups did not differ significantly (gender, age, disease location or past IBD activity, level of PA, or FACIT-F score). The only effect on fatigue from the primary outcome - significant deterioration in FACIT-F score (95%CI:-8.6-(-0.7);p=0.02) - was with omega-3 supplement. Fatigue was however significantly reduced in the exercise groups, measured by IBD-F score (95%CI:-3.8-(-0.2); p=0.03). There were no significant interactions between effects of exercise and fish oil on fatigue, or consistent trends in fatigue or PA levels across the various measures between the four treatment groups. Only 1 treatment-related adverse event was reported (in exercise group), suggesting that neither exercise nor fish oil were associated with likelihood of occurrence of an adverse effect, including gastrointestinal symptoms.

Conclusion: The apparent worsening of fatigue with fish oil is unexplained. Exercise and fish oil, singly or in combination, were shown to be safe and generally well-tolerated in IBD patients. There was no evidence of adverse exercise-related effects on gut-related symptoms, and some evidence of improvement in fatigue. Hence, regular moderate-vigorous exercise may provide self-management options in IBD-related fatigue.

Full paper has been submitted for publication



Crohn's and Colitis UK: Tackling Challenges in IBD-fatigue Report 2014

www.fatigueinibd.co.uk



Inflammatory Bowel Disease-Fatigue (IBD-F) Self-assessment Scale

Date: Time:

SECTION I - Fatigue Assessment Scale

This section of the questionnaire will identify fatigue, its severity, frequency and duration.

Sometimes people with inflammatory bowel disease feel fatigued. The term 'fatigue' is used throughout the questionnaire. Fatigue has been defined as a sense of continuing tiredness, with periods of sudden and overwhelming lack of energy or feeling of exhaustion that is not relieved following rest or sleep.

Please tick ONE number for each question		Score from 0 - 4 with				
		0 = no fatigue			Severe fatigue = 4	
1. What is your fatigue level right NOW		0	1	2	3	4
2. What was your HIGHEST fatigue level in the past two weeks		0	1	2	3	4
3. What was your LOWEST fatigue level in the past two weeks		0	1	2	3	4
4. What was your AVERAGE fatigue level in the past two weeks		0	1	2	3	4
5. How much of your waking time have you felt fatigued in the past two weeks		0 None of the time	1 Some of the time	2 Often	3 Most of the time	4 All the time

IBD-Fatigue Scale.FINAL.30.08.2013

1



SECTION II – IBD-Fatigue Impact on Daily Activities Scale

This section assesses the perceived impact of fatigue on your daily activities in the **past two weeks**.

Please answer all the questions. The possible answers to the questions are: None of the time - 0; Some of the time - 1; Often - 2; Most of the time - 3; All of the time - 4.

If a particular activity does not apply to you, for example you do not drive, please select N/A.

Please tick only ONE answer for each question reflecting on the past two weeks	None of the time	Some of the time	Often	Most of the time	All of the time	Not applicable
1. I had to nap during the day because of fatigue	0	1	2	3	4	
2. Fatigue stopped me from going out to social events	0	1	2	3	4	
3. I was not able to go to work or college because of fatigue	0	1	2	3	4	N/A
4. My performance at work or education was affected by fatigue	0	1	2	3	4	N/A
5. I had problems concentrating because of fatigue	0	1	2	3	4	
6. I had difficulty motivating myself because of fatigue	0	1	2	3	4	
7. I could not wash and dress myself because of fatigue	0	1	2	3	4	
8. I had difficulty with walking because of fatigue	0	1	2	3	4	
9. I was unable to drive as much as I need to because of fatigue	0	1	2	3	4	N/A
10. I was not able to do as much physical exercise as I wanted to because of fatigue	0	1	2	3	4	

IBD-Fatigue Scale.FINAL.30.08.2013

2



Please tick only ONE answer for each question reflecting on the past two weeks	None of the time	Some of the time	Often	Most of the time	All of the time	Not applicable
11. I had difficulty continuing with my hobbies/interests because of fatigue	0	1	2	3	4	
12. My emotional relationship with my partner was affected by fatigue	0	1	2	3	4	N/A
13. My sexual relationship with my partner was affected by fatigue	0	1	2	3	4	N/A
14. My relationship with my children was affected by fatigue	0	1	2	3	4	N/A
15. I was low in mood because of fatigue	0	1	2	3	4	
16. I felt isolated because of fatigue	0	1	2	3	4	
17. My memory was affected because of fatigue	0	1	2	3	4	
18. I made mistakes because of fatigue	0	1	2	3	4	
19. Fatigue made me irritable	0	1	2	3	4	
20. Fatigue made me frustrated	0	1	2	3	4	
21. I got words mixed up because of fatigue	0	1	2	3	4	
22. Fatigue stopped me from enjoying life	0	1	2	3	4	
23. Fatigue stopped me from having a fulfilling life	0	1	2	3	4	
24. My self-esteem was affected by fatigue	0	1	2	3	4	
25. Fatigue affected my confidence	0	1	2	3	4	

IBD-Fatigue Scale.FINAL.30.08.2013

3



Please tick only ONE answer for each question reflecting on the past two weeks	None of the time	Some of the time	Often	Most of the time	All of the time	Not applicable
26. Fatigue made me feel unhappy	0	1	2	3	4	
27. I had difficulties sleeping at night because of fatigue	0	1	2	3	4	
28. Fatigue affected my ability to do all my normal household activities	0	1	2	3	4	
29. I had to ask others for help because of fatigue	0	1	2	3	4	
30. Quality of my life was affected by fatigue	0	1	2	3	4	

SECTION III – Additional Questions about your Fatigue

- What do you think is the main cause of your fatigue apart from IBD?.....
.....
- What do you think are the other causes of your fatigue?.....
.....
- Have you found anything that helps with your fatigue?
.....
- How long have you experienced fatigue?years months
- During this time has your fatigue been: a) Constant b) Intermittent

IBD-Fatigue Scale.FINAL.30.08.2013

4

<http://www.crohnsandcolitis.org.uk/information-and-support/information-about-ibd/publications-list>

Crohn's and Colitis UK Information Sheet

Improving life for
people affected
by inflammatory
bowel diseases



Fatigue and IBD

Introduction

Many people with Ulcerative Colitis (UC) and Crohn's Disease – the two main forms of Inflammatory Bowel Disease (IBD) – suffer from fatigue. This information sheet explains what IBD fatigue is, what may cause it, and possible ways of reducing it.

Much of the research in this information sheet is based on results from the Crohn's and Colitis UK study funded by the Big Lottery Fund. The quotes throughout the information sheet are also taken from this study. More details about the study can be found at the end of this information sheet.

What is fatigue?

Fatigue can be described as an overwhelming sense of continuing tiredness, lack of energy, or feeling of exhaustion which is not relieved after rest or sleep. It is far more than the ordinary and usual tiredness that anyone feels after they have done a lot of physical or mental activity.

'Just feeling very, very weary, and no inner energy...I'm "bone weary" is the old way of describing it.'

Fatigue can be very unpredictable, vary day to day, or even hour by hour. It can come on very suddenly with no warning. People sometimes describe this feeling as like 'hitting a brick wall'.

'I'll be functioning in what I consider to be a perfectly normal way and feeling great one minute. And the next minute, for no reason whatsoever, I'll suddenly drain and have no energy.'

How common is fatigue in IBD?

Fatigue in IBD is very common - over three quarters of people experience fatigue during an IBD flare-up.

There does not seem to be a major difference in the levels of fatigue between people with UC and people with Crohn's. However, some research suggests that fatigue may be worse in people with Crohn's.

Many people find that their fatigue improves as their IBD improves. However, for some, there can be a time lag of weeks or even months before they regain their normal energy levels. Sometimes the fatigue does not go away even when the IBD seems to be completely under control. Fatigue continues to affect over 2 out of 5 people whose IBD is in remission.

What causes fatigue in IBD?

There are many factors which may contribute to fatigue in IBD.

During a flare-up, fatigue may be caused by the body's response to inflammation and illness, combined with

- exhaustion from diarrhoea and repeated toilet visits
- disturbed sleep
- pain
- and anxiety.

tackling the obstacles of fatigue

helping you face life's challenges



IBD fatigue: our new campaign for 2014

Our four-year Big Lottery Funded project on fatigue in IBD is due to be completed this year.

At our AGM in June we will be launching some of the results of the research including a new fatigue rating scale and information video.

Professor Christine Norton of King's College London will give a keynote speech and she will be joined by her colleague Wladzia Czuber-Dochan who has interviewed Crohn's and Colitis patients with IBD fatigue.

She has developed a new fatigue rating scale which can be used by patients and health care professionals.

Our research has confirmed that fatigue is a major symptom of IBD, one which is often overlooked by health care professionals but can have severe implications for quality of life in IBD patients. The project will indicate the way forward for IBD fatigue research and raise awareness of this important issue.

The new campaign - Tackling the Obstacles of Fatigue - highlights some of the ways that IBD patients have described their fatigue and will be developed along with a new-look microsite on fatigue in IBD which will be launched later this year.

In the course of the research we have been helped by nearly 2,000 of our members, and we would like to thank everyone who has participated in the study, or offered their help.



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Appendix II A full copy of the literature review paper on IBD-fatigue

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 Contributor address: King's College London, FRSM, 10th Building, 57 Waterloo Rd, London, UK
 Manuscript number (Editorial office only): APT-1118-2012
 Re: Manuscript entitled Review article: description and management of fatigue in inflammatory bowel disease (the "Contribution")
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C18-6

Review article: description and management of fatigue in inflammatory bowel disease

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SUMMARY

Background

Fatigue is a common and leading concern for patients with inflammatory bowel disease (IBD). It is managed inadequately in IBD, and there is little evidence to support interventions.

Aim

To examine patients' experience of and factors contributing to IBD-fatigue, and to appraise its management by patients and healthcare professionals.

Methods

Seven electronic databases were searched. Subject headings and free-text searching were used, with no time limit set. Reference lists of retrieved papers were searched manually.

Results

Twenty-eight papers were reviewed. Researchers used terms including 'fatigue', 'low energy', 'tiredness', 'decline in vitality and vigour' and 'reduced energy and vitality'. Different definitions were used to conceptualise fatigue. None of the reviewed studies asked patients to describe the experience of fatigue in their own words. Numerous physical, psychological and situational factors associated with fatigue were identified. Three small randomised control trials reported a favourable effect of infliximab and adalimumab on fatigue. One intervention study reported benefit from a stress management programme and one from solution-focused therapy.

Conclusions

Inconsistent use of terminology, lack of data from patients' perspective on IBD-fatigue and lack of evidence to support its management contribute to fatigue being largely ignored or overlooked by healthcare professionals. Future research should explore the experience of IBD-fatigue from the individual patient perspective. Further studies are required to fully explore the factors associated with fatigue and to develop patient-centred interventions to reduce fatigue.

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INTRODUCTION

There is abundant literature describing the pathophysiology and treatment of inflammatory bowel disease (IBD).^{1, 2} However, there is little empirical evidence about people's subjective experience of living with it and how associated symptoms affect their lives.³ People with IBD encounter a variety of symptoms including diarrhoea, pain, abdominal bloating and fatigue.⁴ The symptoms have been described as subjective, unpleasant and distressing.⁵

Several studies have identified fatigue as one of the leading concerns for people with IBD.^{6–8} The most intense concerns relate to physical (energy level) and psychological (patients' perception of achieving full potential) issues.⁹ In a study of concerns reported by 447 Crohn's disease (CD) patients during regular follow-up visits, the three most frequently mentioned concerns were possibility of having an ostomy, energy level and bowel control.¹⁰

A recent systematic review by Van Langenberg and Gibson¹¹ of the literature on fatigue in IBD patients identified that fatigue prevalence ranges from 41% to 48% when disease is in remission, to 86% when it is active. These levels of fatigue are comparable to fatigue in other chronic conditions such as cancer,^{12, 13} multiple sclerosis¹⁴ and rheumatoid arthritis.¹⁵ However, the data on the prevalence of IBD-fatigue were derived from only 254 patients in total and the patients studied were seen in specialist university clinics; therefore, these prevalence ranges might not be representative of the whole IBD patient population.¹¹

The aim of the Van Langenberg and Gibson¹¹ review was to determine prevalence and patterns of fatigue in IBD patients. They found only 10 papers on IBD-fatigue published between 1999 and 2009 and only one of those studies – a study in children – measured fatigue as the primary outcome.¹⁶ In all the other studies they reviewed, measurement of fatigue was secondary to the

main findings of the study. They identified no qualitative studies reporting on the subjective experience and patterns of fatigue and its impact on everyday life in people with IBD, and they concluded that there is an urgent need to understand fatigue better.¹¹

The aim of the literature review reported here was to establish what is known about how people with IBD experience fatigue, and how they and healthcare professionals manage it. The specific questions addressed by the review were:

- (i) How do people with IBD-fatigue describe their experience of fatigue?
- (ii) What factors are associated with presence and severity of IBD-fatigue?
- (iii) What people with IBD and healthcare professionals do to try and manage IBD-fatigue?

MATERIALS AND METHODS

Multiple searches were undertaken using MEDLINE, CINAHL, EMBASE, PsycInfo, BNI, Cochrane and the Web of Science including Science Citation Index (SCI) and Social Science Citation Index (SSCI). Both subject heading searching (MeSH) and free-text searching were used to maximise citation retrieval (Table 1). Due to the limited number of publications on IBD-fatigue, no time limit was set for the papers. The most recent search was performed on 3 August 2012. Searches were limited to 'humans', 'all adult' and English language publications as there was no scope for translation.

The searches yielded 632 references in total (Figure 1). Manual searches were also conducted by scrutinising the reference lists of identified papers. This provided an additional ten papers, previously not identified by the electronic search strategy. Personal communication with authors known to work in the area of fatigue in IBD did not provide any additional papers related to fatigue. Studies of any

Table 1 | Search terms used for literature searching

Fatigue	IBD	Fatigue management	Healthcare professional
fatigue (MeSH)	Inflammatory Bowel	fatigue management	healthcare professional
fatigue*	Disease (MeSH)	management	health care professional
tiredness	IBD*	manage	health professional*
(MeSH) tired*	Colitis (MeSH)		IBD nurse
low energy*	Colitis*		IBD specialist nurse
vigour*	Colitis Ulcerative		gastroenterologist*
vitality*	(MeSH)		general practitioner
	Crohn disease (MeSH)		GP
	Crohn* disease		

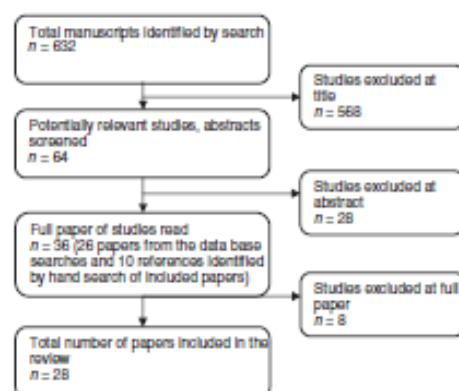


Figure 1 | Citation retrieval and handling process.

design were included if they studied IBD-fatigue in adults, and were published in English. Papers were excluded if they were abstracts, commentary or review papers.

RESULTS

Following scrutiny of titles and abstracts, 36 studies appeared to meet the inclusion criteria. These were read in full by the first author WCD and eight papers were excluded as they were not relevant to the review's aims.^{6–8, 10, 17–20}

Of the 28 remaining studies (see Table S1 for a summary of the papers included in the review) that met the inclusion criteria, 18 were cross-sectional surveys,^{5, 9, 21–36} 5 were randomised control trials (RCTs),^{37–41} 2 were population-based prospective studies,^{42, 43} 1 used a case study design⁴⁴ and 2 were secondary data analyses,^{45, 46} one with qualitative⁴⁶ and the other with quantitative⁴⁵ data. The search strategy and a hand search of the reference lists identified just one study reporting qualitative data⁴⁶ exploring people's subjective experience of IBD and its impact on daily life. Three papers^{30, 31, 36} reported data that were collected during the same study. All three are included in this review as they report data on a different aspect of IBD-fatigue.

Studies were predominantly conducted in hospital out-patient populations. Heterogeneity of design and differences in reporting precluded formal meta-analysis of the outcome of interest, namely IBD-fatigue; therefore, a narrative synthesis of studies is provided.

QUALITY APPRAISAL

The quality of included papers was assessed using the Critical Appraisal Skills Programme (CASP) assessment

Review: fatigue in inflammatory bowel disease

tools specific to the methodological design of each paper,⁴⁷ on the basis of which the studies were classified as high, medium and low quality (see Table S1). Points were deducted if a response rate was low or not reported, if the minimum sample size of participants was not stated or was insufficient for the study design, measurement tools used were not validated, if there were insufficient details provided regarding data analysis or there was evidence of selective reporting. Only three studies (five published papers) were classified as high quality.^{30, 31, 35, 36, 42} However, due to the limited number of studies on IBD-fatigue, no papers were excluded based on their quality.

TERMINOLOGY AND DESCRIPTION OF IBD-FATIGUE

None of the studies asked patients to define or describe the experience of fatigue in their own words. The majority of papers referred to the symptom as IBD-fatigue. However, four others did not use the term 'fatigue', but referred to 'energy level',⁹ 'tiredness',³⁰ 'decline of vitality and vigour'²³ and 'energy and vitality'.⁴⁶ However, none defined these terms. Twelve papers^{5, 20, 30–32, 34–36, 39, 42, 43, 45} provided a definition of fatigue (Table S1). There was a degree of overlap and repetition in the terms used to define fatigue, such as 'reduced physical and mental energy', 'reduced vitality', 'feeling of tiredness', 'reduced energy level' (not specified if mental or physical energy), 'reduced muscle strength' and 'cognitive impairment'.

PREVALENCE OF IBD-FATIGUE

Studies published since Van Langenberg and Gibson's review in 2009¹¹ have presented new data on the prevalence of IBD-fatigue. Reported fatigue prevalence in ulcerative colitis (UC) patients in remission varied from 22%,³⁰ 30%⁴⁵ to 36%,⁴² and in CD patients from 27%,²² 29%,³⁰ 30%,⁴³ 38%⁴² to 41%.⁵ Fatigue prevalence was reported as 36% for CD patients in remission without irritable bowel syndrome (IBS)-like symptoms; however, it was much higher, at 60%, if CD patients were also diagnosed with IBS-like symptoms.²⁹

Fatigue prevalence in patients with active CD was reported at 86%³⁹; however, the sample size was very small ($n = 14$) and the patients were presenting with very complex disease. In the two larger studies^{42, 43} with active CD patients, fatigue prevalence was reported as 77% ($n = 143$) and 72% ($n = 318$ CD) respectively. Three studies with a mixed disease activity population reported fatigue at 44%,³⁵ 50%³³ and 64%.³²

W. Czubier-Dochan *et al.*

One study³³ compared patients' concerns and feelings with the perceptions of their close relations and physicians. Sixty-six per cent of patients reported fatigue as a daily concern, but only 36% of physicians and 44% of close relations were in agreement in terms of patient's fatigue level and the effort needed to maintain their daily activities.

TYPES AND INTENSITY OF IBD-FATIGUE AND TOOLS USED TO MEASURE FATIGUE

Fatigue is a multidimensional symptom and most of the studies referred to different dimensions of fatigue. The classification of types of fatigue or types of functioning reflected the assessment scales used (Tables 2 and 3). Five different scales were used in 15 studies to measure fatigue. The most frequently employed was the Multidimensional Fatigue Inventory (MFI), used in eight studies. Four scales measuring type of functioning were used by 16 different studies. Many studies utilised more than one scale to collect the data. In total, nine fatigue scales were used; however, the rationale for choosing a specific scale was often not provided. The scales had been developed with the general population or other chronic conditions, and most had not previously been tested with an IBD population.

Two studies that used the MFI, adopted different cut-off points to diagnose fatigue; one⁴² used a cut-off of 14 points and the other,⁵ 13 points. Studies referred to chronic fatigue, total fatigue and substantial fatigue; however, often the terms were not defined or explained.

FACTORS ASSOCIATED WITH IBD-FATIGUE

Factors contributing to the development or severity of fatigue may include physical, psychological and situational factors (Tables 4–6). The associations between fatigue and other variables such as gender,^{26, 42, 48} duration of illness,^{23, 28, 30} anaemia,^{5, 26, 30, 35, 42, 43} pain^{21, 25} and sleep pattern^{26, 27, 30, 43, 46} are not well understood, with conflicting data being reported. Several studies identified a correlation between the severity of IBD symptoms and the presence and severity of fatigue^{21, 30, 39, 45}; however, other studies reported fatigue when IBD was in remission.^{5, 21}

PHYSICAL FACTORS

Numerous physical factors were identified across the studies as associated with IBD-fatigue (Table 4). Data on age and gender, although frequently measured, were not found to be associated with fatigue, except in one study

Table 2 | Tools measuring types of fatigue in IBD studies

Table 2 Tools measuring types of fatigue in IBD studies							
Tool	Types of fatigue						Studies using tool
	Physical fatigue	Mental fatigue	General fatigue	Reduced activity	Reduced motivation	Emotional fatigue	
MFI	✓	✓	✓	✓	✓	✓	Minderhoud et al. (2003, 2007), Banovic et al. (2010), Bol et al. (2010), Romberg-Camps et al. (2010), Graff et al. (2011), Lesage et al. (2011), Bager et al. (2012) (n = 8)
FACT-F	✓	✓	✓	✓	✓	✓	Loftus et al. (2008), Tinsley et al. (2011) (n = 2)
FQ	✓	✓	✓	✓	✓	✓	Jelness-Jørgensen et al. (2010, 2011, 2012) (n = 3)
PFS	✓	✓	✓	✓	✓	✓	Romkens et al. (2011) (n = 1)
CIS	✓	✓	✓	✓	✓	✓	Vogelaar et al. (2011) (n = 1)
MFI, Multidimensional Fatigue Inventory; FACT-F, Functional Assessment of Chronic Illness Therapy-Fatigue; FQ, Fatigue Questionnaire; PFS, Piper Fatigue Scale; CIS, Credentia Individual Strength.							

Table 3 Tools measuring types of functioning in studies of IBD fatigue							
Tool	Types of functioning					Total fatigue	Studies using tool
	Physical functioning	Cognitive functioning	Psychosocial functioning	Social functioning	Emotional functioning		
FIS	✓	✓	✓			✓	Bjornsson et al. (2004), Kalaitzakis et al. (2008), Simren et al. (2008), Piche et al. (2010) (n = 4)
SF-36	✓	✓		✓	✓		Jelness-Jorgensen et al. (2010, 2011, 2012), Hauser et al. (2005), Kalaitzakis et al. (2008), Banovic et al. (2010), Romberg-Camps et al. (2010) (n = 7)
GSCL (fatigue subscale)	✓	✓		✓	✓		Hauser et al. (2005) (n = 1)
IBDQ				✓	✓	✓	Minderhoud et al. (2003, 2007), Jelness-Jorgensen et al. (2010, 2011, 2012), Romberg-Camps et al. (2010) (n = 6)

FIS, Fatigue Impact Scale; SF-36, Health Survey Short Form-36; GSCL (fatigue), Short Form Gieseen Subjective Complaints List; IBDQ, Inflammatory Bowel Disease Questionnaire.

where greater age related to a higher level of fatigue in females with UC.³⁵ Female gender was identified in only two studies^{24, 42} as being significantly associated with higher fatigue level. Disease activity was the only physical factor that was consistently associated with presence and severity of fatigue; people with active disease had significant higher levels of fatigue.

Some studies reported that medications used to treat IBD were associated with greater levels of fatigue. One study identified an association between the presence of fatigue and the increased use of immunomodulators, such as azathioprine (AZA) and methotrexate ($P = 0.024$), but there was no difference observed between fatigue and the use of tumour necrosis factor-alpha inhibitors, 5-aminosalicylic acid or prednisolone.³¹ The link between the use of thiopurines (AZA or mercaptopurine) and the onset of severe fatigue was also suggested by five case studies, with rapid fatigue relief on the withdrawal of medication.⁴⁴

Current use of corticosteroids and immunosuppressives was not identified as a determining factor for presence or severity of fatigue.⁴²

PSYCHOLOGICAL FACTORS

Psychological factors, such as anxiety, depression, stress, quality of life and an emotional way of coping with illness, were all associated with fatigue (Table 5); however, only anxiety and depression were consistently associated with it.^{21, 25, 27, 28, 31, 45} There was a positive association between anxiety, depression and fatigue; however, the direction of causation is not clear.

SITUATIONAL FACTORS

Situational factors such as level of education, relationship status and living circumstances were not associated with fatigue level; however, unemployment, financial difficulties, social support and people's perception of achieving full potential were (Table 6). It has been shown that people with a better support system report lower levels of fatigue.²³ It is not clear if this support relates to physical activities such as shopping, cooking, driving or more psychological types of support.

METHODS OF MANAGING IBD-FATIGUE

Nonpharmacological management

Two RCT studies evaluated nonpharmacological interventions for managing IBD-fatigue. One³⁸ compared professionally led stress management, self-directed stress management and conventional medical treatment.

Table 4 | Physical factors associated with IBD-fatigue (P values reported)

Factors associated with IBD-fatigue	First author and year of publication										
	Minderhoud (2003)	Bommission (2004)	Hauser (2005)	Tenaka (2005)	Kalatzakis (2005)	Srinen (2008)	Wafu (2008)	Bannic (2008)	Bul (2010)	Johannis-Jorgensen (2010)	Piche (2010)
Age	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Gender – Female	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Disease activity/severity	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Length of time since diagnosis	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Disease type	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Number of relapses	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Other problems and comorbidity (asthma, IBS-like symptoms)	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Pain, use of analgesics or opiates	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Ostomy	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Short bowel syndrome	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Sleep difficulties	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Anaemia	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
CRP	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Plasma	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Albumin	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Basal cortisol level	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
General health	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
BMI	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Physical functioning	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.
Home parental nutrition	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.	N.S.

N.S., not significant; sig*, reported as significant in discussion, but value not stated in the results; CRP, C-reactive protein; BMI, body mass index; –ve, negative correlation; +ve, positive correlation between fatigue and reported factor.

Table 5 Psychological factors associated with IBD-fatigue (P values)										
First author and year of publication										
Factors associated with IBD-fatigue	Minderhoud (2003)	Bjornsson (2004)	Hauser (2005)	Tanaka (2005)	Kalaitzakis (2008)	Simen (2008)	Banovic (2010)	Bol (2010)	Graff (2011)	Jelness-Jorgensen (2012)
Factors associated with IBD-fatigue										
HAD-Anxiety					+ve 0.007		N.S.			
HAD-Depression		+ve 0.001	+ve 0.01		+ve 0.018		N.S.	+ve 0.01		
Quality of life	-ve 0.001				-ve 0.001					-ve 0.001
Social functioning			-ve 0.0001							
Psychological well-being						-ve 0.0001				
Stress, emotive coping				+ve 0.05				+ve 0.01	+ve 0.001	+ve 0.01
HAD, Hospital Anxiety & Depression Scale.										

Table 6 Situational factors associated with IBD-fatigue (P values)						
Factors associated with IBD-fatigue	First author and year of publication					
	de Rooy (2001)	Hauser (2005)	Tanaka (2005)	Simen (2008)	Jelness-Jorgensen (2010)	Jelness-Jorgensen (2012)
Unemployed, financial difficulties	+ve 0.0001			+ve 0.0001	N.S.	+ve 0.05
Level of education				N.S.	N.S.	
Achieving full potential	-ve 0.0001					-ve 0.05
Marital/relationship status				N.S.		
Social support			-ve 0.05			
Living alone				N.S.		
Role limitation – physical functioning		-ve 0.004				

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Forty-five CD patients were randomly allocated to three equal-sized treatment groups with outcome measures after treatment and at 6 and 12 months. Only the self-directed stress management group presented a small, but not significant, reduction of fatigue ($P < 0.10$) after treatment and at 6 and 12 months' follow-up, compared with those in the other groups. Authors of the study incorrectly reported the P value as statistically significant.

The second RCT⁴¹ compared problem-solving therapy, solution-focused therapy and usual treatment. The interventions were delivered by an expert psychotherapist. Ten patients were included in each intervention arm, and 20 patients in the control group. However, due to attrition, the data were only analysed for 7 patients in the solution-focused therapy, 5 patients in the problem-solving therapy and 11 patients in the control group. Six patients in the solution-focused therapy group and three patients in the problem-solving therapy group reported a reduction of fatigue from baseline to 3 months' follow-up.

Pharmacological management

Two RCT studies examined the effect of infliximab on fatigue in patients with active CD^{37, 39} and another evaluated the effects of adalimumab maintenance therapy on health-related quality of life in patients with moderate to severe CD.⁴⁰

In the first RCT,³⁷ participants were randomised to one of four arms: placebo, a single dose of infliximab of 5 mg/kg, a single dose of infliximab of 10 mg/kg and a single dose of infliximab of 20 mg/kg. A significantly larger proportion of infliximab patients, in comparison with the placebo group, reported having full or a lot of energy ($P = 0.013$), with no or hardly any difficulty doing sport or leisure activities ($P = 0.011$) and being very satisfied with their personal life ($P = 0.046$). They also reported significant improvements regarding fatigue ($P = 0.038$). No relationship was found between the infliximab dose and the proportion of patients responding to it.

The second RCT³⁹ examined the effect of infliximab on fatigue in CD patients. Fourteen patients took part and all received placebo at baseline, followed by 5 mg/kg infliximab at 2 weeks. Fatigue scores on the MFI scale were significantly lower ($P < 0.05$), after both placebo and infliximab infusion compared with the baseline. The authors conclude that fatigue reduction is subject to a placebo effect; however, placebo has a short-term effect. The effect of infliximab on IBD-fatigue was reported as a longer lasting effect, although this conclusion should be questioned on the grounds of small sample size ($n = 14$) and selective reporting.

In the third study,⁴⁰ patients who positively responded to adalimumab treatment ($n = 492$ CD) were randomised into three treatment arms: adalimumab at induction only, 40 mg adalimumab every week and 40 mg adalimumab every other week, and were followed up for 56 weeks. All three groups reported a significant reduction of fatigue on Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F) scale after the induction injection of adalimumab ($P < 0.0001$). From week 12 onwards, the induction-only arm reported worsening of fatigue at the subsequent visits. The weekly adalimumab group reported slight, but not significant, improvements of fatigue at weeks 12, 26 and 56. The every other week arm reported significant ($P < 0.001$) improvements in fatigue above the baseline, at week 12 and onwards. There was no significant difference between the adalimumab every week and every other week arm except at week 12.

DISCUSSION

In total, 28 papers were reviewed, but only three studies (five published papers) were classified as high-quality studies. In the majority of the studies, fatigue was measured as a secondary outcome, rather than the primary focus of the investigation. All but one paper were quantitative. The only qualitative data came from a mainly quantitative study,⁴⁶ which aimed to identify how IBD affected an individual's daily life, and therefore information relating to IBD-fatigue was very limited. Almost half of the papers were published in the last three years, indicating an increased interest in IBD-fatigue.

This literature review highlights a lack of clarity in the terminology used and conceptualisation of the symptom of IBD-fatigue. Due to the varied terminology used, it is difficult to ascertain if all studies are dealing with the same phenomena. It is unclear if the different terms used, such as 'tired', 'fatigued', 'lack of energy' or 'lack of vitality and vigour', have the same meaning for both patients and health professionals and can be used interchangeably. Several authors noted the uncertainty surrounding the symptom of fatigue and the lack of agreement on its definitions, and this may have led to fatigue being considered by health practitioners as having little clinical importance. A concept analysis of fatigue in cancer⁴⁹ concluded that there are different definitions of fatigue used in colloquial and scientific language. There is a clear need for better elucidation and explanation of the symptom of fatigue and more standardised patient-focused definitions.

A study²⁸ comparing fatigue in multiple sclerosis and UC patients identified that, although rates of fatigue were higher in multiple sclerosis than in UC, the factors

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associated with fatigue did not indicate multiple sclerosis specificity. This suggests that there are similarities in experience and in the constructs of fatigue between the two conditions, and that a trans-diagnostic approach to fatigue may contribute to its better understanding.

In the earlier literature review by Van Langenberg and Gibson covering the period prior to 2009,¹¹ fatigue was reported to affect 41–48% of patients in remission, and 86% in active disease. However, the data were derived from only 254 IBD patients treated in specialised university clinics. The studies published since 2009 (the date of the last review) confirm fatigue prevalence in IBD, both in remission 22–41%^{5, 30} and in moderate to active disease 44–86%,^{35, 39} with data derived from a total of 6165 IBD patients, from sixteen studies, with a variety of specialised university clinics and a community-based IBD register. The IBD-fatigue prevalence rates are comparable with rates of fatigue in other chronic conditions, for example, 40–89% in cancer,^{12, 50} 75–78% in multiple sclerosis^{51, 52} and 41–76% in rheumatoid arthritis patients,⁵³ although, fatigue in IBD has not received the same amount of attention in research and clinical practice as fatigue in other conditions.

The different aspects of fatigue in terms of type (physical, mental, cognitive emotional), duration (acute, chronic), severity (mild, moderate, substantial, severe) and pattern (Tables 2 and 3) reflect and confirm its multidimensional nature.⁵⁴ The different types of fatigue and types of functioning reported on are closely related to the fatigue scales used in the different studies. As there are no qualitative data generated from patients' experience of fatigue, it is not clear whether the specific fatigue assessment tools used reflect the types of fatigue experienced as reported by patients. Current fatigue assessment tools cover both the type of fatigue and the effect fatigue has on individual's functioning for example psychological functioning (e.g. reduced motivation) or physical functioning (e.g. reduced activity). Literature in cancer suggests classifying fatigue on the basis of its severity, for example, tired, fatigued and exhausted.⁵⁵

The many different fatigue assessment tools suggest a lack of clarity about what tool(s) should be used. Currently, there is no evidence on how to measure fatigue in IBD, and which tool(s) to use. This may account for the reluctance of health practitioners to assess fatigue frequently and systematically. Of the nine fatigue tools used by the reviewed studies, all (except IBDQ – which measures quality of life in IBD and only has one question each on fatigue and level of energy) were developed with non-IBD populations, and most, except FACIT-F,³⁴ have not been validated with IBD patients. Most authors

described the fatigue scale used, but provided no rationale for selecting the specific tool. There is an urgent need to validate the tools used with IBD patients, confirming their validity and specificity to this population.

Multiple correlates of fatigue have been identified and measured. There is evidence of clinical and demographic factors contributing to IBD-fatigue severity, but with lack of consistency between the different variables measured. Most frequently measured were age, gender and disease activity, but only increased disease activity was consistently associated with a greater level of fatigue,^{21, 26, 28–30, 34, 35, 43, 45} but disease activity alone cannot explain the large proportion of patients in remission still being affected by fatigue.

The other frequently reported factors related to fatigue were sleep and anaemia. Sleep disturbance in terms of quality, duration and altered sleep pattern in IBD patients may be related to the need to use the toilet at night or worry about being incontinent in bed. IBD patients have significant sleep disturbance even in remission.^{20, 56} Like other medical conditions with underlying inflammation, IBD is associated with a cluster of symptoms such as fatigue, sleep disturbance, depression and loss of appetite.^{57–60} Studies in other conditions as well as in the general population have demonstrated that sleep problems and inadequate sleep have a major impact on health-related quality of life, fatigue and energy level.^{61–63}

Anaemia is one of the most prevalent complications of IBD, affecting 16% of out-patients and 68% of hospitalised patients.^{64, 65} Iron deficiency anaemia is the most common cause of anaemia in IBD.⁶⁶ Assessment of iron status in IBD patients by using common biochemical values is insufficient and more specific tests, for example, ferritin level, transferrin receptor ratio and others, are being recommended to diagnose and treat anaemia with intravenous iron administration.⁶⁴

Other factors such as being newly diagnosed, pain and other co-morbidities were reported as factors contributing to the level of fatigue by some studies, but not supported by others. It is interesting that in a condition related to the digestive system, nutritional factors and the impact of diet on fatigue were not studied.

Anxiety, depression^{21, 25, 28, 45} and stress^{23, 28, 36, 43} were consistently associated with fatigue. Patients who are diagnosed with depression also report higher levels of fatigue, but not all fatigued patients report stress and depression. It is difficult to ascertain if anxiety and depression are the cause of fatigue, or its outcome, or can each interact with the other.^{67–70} Fatigue impacts on functional and cognitive performance and three studies

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demonstrated reduced quality of life in people with IBD-fatigue.^{5, 25, 31} Good social functioning and social support have been identified as beneficial in relation to fatigue.⁴⁵ People with chronic conditions, particularly those with embarrassing symptoms such as diarrhoea, frequency of defecation and a low level of energy, may intentionally exclude themselves from social situations. The long-term consequences of fatigue in IBD have not been studied. Information on the long-term, cumulative effects of IBD-fatigue would enable better patient assessment and for the development of fatigue interventions. Particular symptoms tend to occur together for example, fatigue, depression, pain and diarrhoea. However, the combination of the symptoms and the relationship between them is not well understood. Future research should have a multiple symptom focus. Delineating the contribution of physical and psychological variables in relation to fatigue severity and its impact may give a better understanding of how to be more effective with self-management, and help health professionals to meet the needs of people living with IBD-fatigue.

Only two studies on IBD-fatigue reported nonpharmacological interventions: a stress management programme³⁸ and problem-solving therapy.⁴¹ Other systematic reviews of nonpharmacological interventions in cancer, multiple sclerosis and rheumatoid arthritis have identified many physical (exercise, walking) and psychosocial interventions (counselling, stress management, coping strategies) as potentially beneficial in reducing the level of fatigue.^{71, 72} Further research is needed in this area to test interventions with IBD patients.

Infliximab^{37, 39} and adalimumab⁴⁰ were identified as having possible positive therapeutic effect on fatigue. Infliximab 5 mg/kg appears to be effective in reducing fatigue, and adalimumab 40 mg administered every other week appears to be most clinically effective in reducing fatigue in patients with CD who are already known to respond to adalimumab treatment. However, the high cost and possible side effects of the medications might prohibit them from being included as mainstream treatments for IBD-fatigue. The studies only included patients' with CD, and the effect on UC is unknown.

CONCLUSIONS

The reviewed literature offers incomplete information as to the causes, severity and ways of measuring IBD-fatigue.

As there are currently no patient generated descriptions of IBD-fatigue in the literature, this suggests the need for studies on fatigue as experienced by people with IBD. It is important that easily reversible causes of fatigue are identified and treated, to prevent unnecessary patients' distress and suffering, and before more time and resource consuming investigations are undertaken. If the predictors of fatigue could be identified through research, then the individuals most at risk could be targeted and preventative measures employed. Also, methods of managing fatigue need to be further explored. The multidimensional nature of fatigue can only be addressed through the combination of different approaches; therefore, complex intervention studies are required.

AUTHORSHIP

Guarantor of the article: W. Czubier-Dochan

Author contributions: Study design CN, WCD; Literature search and review WCD; Selection of papers and discussion of findings WCD, ER, CN; First draft preparation WCD; Final draft WCD, ER, CN. All authors approved the final version of the manuscript.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Table S1. Papers included in literature review (in ascending chronological order).

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Appendix III Data extracted from the reviewed papers on IBD-fatigue

(In ascending chronological order)

Author & Year	Aims of the study	Design	Sample size	Fatigue definition & tools used to measure fatigue	Findings	Study quality
1. De Rooy et al 2001, Canada	Determine the leading concerns of IBD outpatients	Cross sectional survey	241 IBD (UC/CD 121/120)	-No definition of fatigue provided -Fatigue not measured	- Energy level was concern number 1 for patients with CD, and concern number 2 for patients with UC	Low
2.Lichtenste in et al 2002, USA	Assess the effect of infliximab on quality of life in patients with active CD	RCT, double-blinded multiple centre	83 CD	-No definition of fatigue provided -IBDQ	- Placebo and actively treated patients reported symptom improvement - Infliximab improved quality of life and decreased feelings of fatigue	Low
3.Minderh ud et al 2003, The Netherlands	To assess the prevalence and severity of fatigue in IBD patients in remission	Cross sectional survey	80 IBD	-The 95 percentile of the score on the general fatigue scale of the healthy control group; MFI, IBDQ	41% of IBD patients in remission suffered from fatigue	Medium
4. Bjornsson et al 2004, Sweden & UK	To evaluate general well-being in patients with primary sclerosing cholangitis (PSC) with particular focus on fatigue in comparison with IBD alone and matched with general population	Cross sectional survey	151 IBD from two hospitals, one in the UK and one in Sweden	-No definition of fatigue provided -FIS	- Fatigue scores higher in PSC and IBD, than IBD alone, - Fatigue scores did not differ significantly between PSC and IBD alone - Depression, gastrointestinal symptoms and general health were independent predictors for total fatigue score in PSC - Both the PSC and IBD patients reported lower fatigue scores than subjects from the general population	Low
5.Garcia-Vega & Fernandez-Rodriguez 2004, Spain	To assess effectiveness of stress management technique in reducing disease activity and improving psychosocial functioning in CD patients	RCT	45 CD	-No definition of fatigue provided -Semi-structured protocol designed by the authors	- The self-directed stress management reported significantly reducing tiredness post-treatment and at 6 and 12 months post-treatment, however significance is reported as $p<0.1$ - Medical treatment plus psychological treatment seems to be more effective than medical treatment alone - 20% of stress management groups successfully learned the confrontation strategies	Medium
6. Hauser et al 2005, Germany	To identify determinants of fatigue in IBD-outpatients in remission or with slight disease activity	Quantitative-Secondary data analysis	37 UC with IPAA and 40 UC without ileal	-Fatigue defined as subjective experience of reduced physical and/or mental energy/vitality	- 30% of UC patients suffered from a level of fatigue higher than the general population -Fatigue had significant predictive value for reduced physical and social functioning	Low

Author & Year	Aims of the study	Design	Sample size	Fatigue definition & tools used to measure fatigue	Findings	Study quality
			pouch-anal anastomosis	-GSCL (fatigue subscale),SF-36	- Fatigue in UC patients is independent from objective disease measures in quiescent disease - Disease activity and depression are predictors of fatigue	
7. Hershfield 2005, Canada	To explore if IBS and IBD patients differ in their reporting of non-gastrointestinal symptoms	Cross sectional survey	200 IBS & 200 CD	-No definition of fatigue provided -Questionnaire developed by the author	Prevalence of fatigue in CD patients was reported at 27%	Low
8.Tanaka & Kazuma 2005, Japan	Elucidate factors influencing perception of difficulties of life and psychological well being of patients with UC in remission	Cross sectional survey	72 UC	-No definition of fatigue provided -Questionnaire developed by the authors	- Emotive coping, low social support and high difficulties in life influence the scores for fatigue - Many patients perceived a decline of vitality and vigour despite being in the remission - It takes long time to resolve the decline of vitality or vigour	Low
9 Minderhoud et al 2007, The Netherlands	To measure the effect of infliximab on fatigue, clinical disease activity and depression scores	RCT Single blinded study	14 CD	-The 95 percentile of the score on the general fatigue scale of a healthy control group, a score of 13 or higher indicates 'fatigue' -MFI, IBDQ,	- Baseline fatigue prevalence 86% - Fatigue was significantly reduced by administration of a single dose of infliximab (patients with fistulae received one extra dose of infliximab 4 weeks after baseline)	Low
10. Joyce et al 2008, USA	To determine which symptom domains are frequent and responsive to change of disease activity	Cross sectional survey	60 UC	-No definition of fatigue provided - Questionnaire developed by the authors	- Fatigue was responsive to change in disease activity and treatment - Fatigue is not included in a standard assessment	Medium
11.Kalaitzakis et al 2008, Sweden	Assess potential relation between fatigue and gastrointestinal symptoms in short bowel syndrome (SBS)	Cross sectional survey	26 short-bowel syndrome (CD/UC 22/2), 41 IBD (CD/UC- 13/28), 286 healthy controls	-No definition of fatigue provided -FIS, SF-36	- Patients with SBS had more severe fatigue and gastrointestinal symptoms compared with IBD controls - Fatigue has a negative impact on Quality of Life (QoL)	Low

Author & Year	Aims of the study	Design	Sample size	Fatigue definition & tools used to measure fatigue	Findings	Study quality
12. Loftus et al 2008, USA, Canada, France, Australia & South Africa	To evaluate the effects of adalimumab maintenance therapy on HRQoL in patients with moderate to severe CD	RCT double-blinded, multicentre study	854 CD	-No definition of fatigue provided -FACIT-F, IBDQ, SF-36	- At baseline patients' mean fatigue scores were 22.9 points, approximately half of the average score for the US general population, and similar to scores of patients with Ca-related anaemia - This study presents the first evidence of a biological agent reducing symptoms of fatigue and depression in patients with CD	Medium
13. Simren et al 2008, Sweden	Evaluate factors of importance for fatigue in patients with chronic gastrointestinal diseases (IBS & IBD)	Cross sectional survey	223 IBD (UC/CD 133/90), 112 IBS	-No definition of fatigue provided -FIS	- Patients with IBS and IBD were more fatigued than controls - Patients with IBS were more fatigued than patients with IBD - Psychological well-being, sleep disturbances and employment status were independently associated with the severity of fatigue	Medium
14. Wolfe & Sirois 2008, Canada	Examine IBD pts' subjective experiences of HRQoL affected by IBD, as identified by pts themselves	Qualitative research secondary analysis	282 IBD	-No definition of fatigue provided -Participants answered open ended question: 'How has IBD affected your daily activities?'	- Energy and vitality was a concern of many participants - Fatigue and lack of energy contributed to the inability of many participants to carry out normal tasks - Other people, including medical professionals, do not understand or value patients' experience	Low
15. Lee et al 2009, Australia	To describe the clinical scenario of a series of patients where thiopurines were the likely cause of fatigue	Case study	5 IBD	-No definition of fatigue provided -Not clear how fatigue was assessed	-Thiopurines use is a likely cause of severe fatigue and lethargy -The onset of fatigue was closely related to the initiation of thiopurines -The mechanism of how thiopurines cause fatigue is unknown -Thiopurine-induced fatigue resolves rapidly	Low
16. Banovic et al 2010, France	Assess fatigue, disease activity, depression and anxiety, sleep disturbances, and subjective QoL	Cross sectional survey	52 CD	-No definition of fatigue provided -MFI	- Age and gender did not influence fatigue - Patients described themselves as tired and having unsatisfactory general health One year later: - Disease was inactive and there was no difference in fatigue score - No significant difference between the two visits on the assessments of depression, anxiety, sleep disturbances, and subjective QoL	Low

Author & Year	Aims of the study	Design	Sample size	Fatigue definition & tools used to measure fatigue	Findings	Study quality
17. Bol et al 2010, The Netherlands	To study the disease specificity of fatigue in multiple sclerosis (MS) and comparing its level with UC	Cross sectional survey	76 UC & 88 MS	-Only fatigue in MS was defined as a subjective experience, with psychological variables being expected to contribute to MS-fatigue; Fatigue in UC not defined -MFI	- On average MS patients had higher scores on physical and mental fatigue and depression than the UC patients - Physical fatigue in both MS and UC patients significantly correlated with disease severity, depression, and negative affectivity, but not with age and gender	Medium
18. Jelsness-Jorgensen et al 2010, Norway	Estimate the level and frequency of fatigue among patients with mild to moderate IBD compared with healthy controls	Cross sectional survey	140 IBD patients (UC/CD 92/48) & 2287 healthy controls	-A feeling of tiredness, reduced energy levels, reduced muscles strength, and cognitive impairment; fatigue referred to as weakness, lack of energy, and tiredness -FQ, IBDQ	- UC & CD patients reported significantly increased fatigue symptom compared to healthy controls - Substantial fatigue reported in 22% HC, 52% CD and 50% UC - Chronic fatigue was reported by 29% CD & 22% UC patients - Age, gender, employment, nor education had statistically significant impact on fatigue - IBD symptoms, haemoglobin levels, and altered sleep patterns are significant predictors of chronic fatigue	High
19. Piche et al 2010, France	To investigate the prevalence of IBS-like symptoms in CD patients with long-lasting remission and impact of IBS-like symptoms on fatigue and QoL	Cross sectional survey	92 quiescent CD, 40 IBS and 20 healthy subjects	-No definition of fatigue provided -FIS	- Fatigue was reported by patients with IBS (55%), CD patients with IBS-like symptoms (60%), CD patients without IBS-like symptoms (36%) and healthy subjects (25%) - The study found significant correlations between the severity of symptoms and QoL, the severity of fatigue, depression, and anxiety in both IBS and CD patients	Medium
20. Romberg-Camps et al 2010, The Netherlands	To investigate the prevalence and severity of fatigue and the impact on HRQoL	Population based IBD registry prospective study	707/1084 questionnaires (304 CD, 368 UC and 35 indeterminate colitis)	-95 percentile of the general fatigue subscale of the general population, and a cut off level 14 on MFI scale -MFI, IBDQ, SF-36	- The prevalence of fatigue was nearly 40% in remission - Disease activity and anaemia were positively related with the level of fatigue - Disease activity as well as fatigue were independently associated with HRQoL - Despite the high prevalence of fatigue in IBD, this symptom remains poorly understood	High
21. Graff et al 2011, Canada	To evaluate psychological and biological factors in relation to fatigue	Population based IBD cohort study	318 CD	-An overwhelming sense of tiredness, lack of energy and feeling of exhaustion with impaired physical	-72% with active and 30% with inactive disease reached clinical threshold for fatigue -77% with active and 49% with inactive disease experienced poor sleep	Medium

Author & Year	Aims of the study	Design	Sample size	Fatigue definition & tools used to measure fatigue	Findings	Study quality
				and/or cognitive functioning, incorporating sense of physical depletion and interference -MFI	-Disease activity , poor sleep (but not hours of sleep) and perceived stress were associated with elevated fatigue	
22. Jelsness-Jorgensen et al 2011, Norway	To investigate the influence of chronic fatigue on generic and disease-specific HRQoL	Cross sectional survey	140 IBD (UC/CD 92/48)	-Feeling of tiredness, reduced energy, reduced muscle strength and cognitive impairment. Fatigue may be a natural and transient part of life. Chronic fatigue (CF) is regarded as > 6 months -FQ, SF-36, IBDQ	- CF was associated with increased IBD symptoms, smoking and haemoglobin values - CF was associated with reduced scores in general health - CF significantly affects IBD patients' daily life - CF is associated with a reduction in HRQoL scores in IBD with CD patients being more affected than UC patients	Data reported from the same study as Jelsness-Jorgensen et al 2010 and 2012
23. Lesage et al 2011, France	To learn about patients' concerns and to compare their feelings with the beliefs of their relations and physicians	Cross sectional survey	2424 IBD	-No definition of fatigue provided -MFI	-IBD was responsible for fatigue and had a negative impact on daily, occupational, leisure, family and personal life -Fatigue was independent of the presence or not of a flare-up, 50% of the patients were fatigue, but only 23% were having a flare-up -Fatigue and low energy were the greatest patients' concerns (66%), but 77% of patients wanted to maintain their level of activity -Physicians and relatives greatly underestimate the feeling of fatigue, and only beginning to become more aware of fatigue	Medium
24. Romkens et al 2011, The Netherlands	To assess the prevalence and possible determinants of fatigue in IBD outpatients	Cross sectional survey	117 CD & 55 UC	-Chronic fatigue (CF) was defined as unpleasant, unusual, abnormal, excessive whole-body tiredness, disproportionate to or unrelated to activity or exertion for more than one month. CF is constant or recurrent, which is not dispelled easily by sleep or rest and can have a	-64% reported fatigue regardless of clinical activity; 40% in clinical remission (HBI≤5) reported fatigue -None of the studied determinants of fatigue were significantly correlated with the presence of fatigue	Medium

Author & Year	Aims of the study	Design	Sample size	Fatigue definition & tools used to measure fatigue	Findings	Study quality
				profound negative impact on the person's QoL -PFS		
25. Tinsley et al 2011, USA	To validate the Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F) scale in IBD	Cross sectional survey	209 IBD	-Fatigue represents an overwhelming, sustained sense of exhaustion and decreased capacity for physical and mental work -FACIT-F	-FACIT-F scale is valid and reliable instrument to measure fatigue with CD and UC -Patients with CD and UC have lower FACIT-F score and therefore experience more fatigue than the general population $p < 0.001$. A difference of 3-4 units is considered a minimal clinically important difference. -IBD patients with quiescent disease have higher levels of fatigue than the general population	Medium
26. Vogelaar et al 2011, The Netherlands	To assess the feasibility and effect of psychological interventions in the management of fatigue	RCT- pilot study	29 CD	-No definition of fatigue provided -CIS	-Solution Focused Therapy group - fatigue level improved in six out of ten patients, in Problem Solving Therapy group - three of patients improved fatigue scores, and in the Treatment as Usual group - five out of eleven patients improved fatigue from baseline to 3 months follow up -Solution Focused Therapy had a positive effect on fatigue, better quality of life and fewer visits to the outpatient clinic	Medium
27. Bager et al 2012, Denmark, Sweden & Norway	To investigate the prevalence, characteristics and determinants of fatigue in IBD	Cross sectional study	437 IBD	-Persistent, overwhelming sense of tiredness, weakness or exhaustion resulting in a decreased capacity for physical and/or mental work -MFI	-44% of the cohort had general fatigue (29% with no disease activity and 57% of patients with active disease) -The fatigue scores were not significantly different between the UC and CD patients -Fatigue in IBD is common regardless of anaemia or iron deficiency, and is most marked for patients <60 years of age -Stratifying for age and gender is necessary, as fatigue is expressed differently between groups	High
28. Jelsness-Jorgensen	To examine the impact of fatigue on disease-related worries in IBD	Cross sectional survey	140 IBD (UC/CD 92/48)	-Chronic fatigue was defined as an elevated fatigue level (4 points or	-Increased levels of worrying were associated with increased fatigue levels and reduced HRQoL.	Data reported from the

Author & Year	Aims of the study	Design	Sample size	Fatigue definition & tools used to measure fatigue	Findings	Study quality
et al 2012, Norway				more) and duration longer than six months -FQ, SF-36, IBDQ	-The cause /effect relationship between HRQoL and increased worries and fatigue is not clear	same study as Jelsness-Jorgensen et al 2010 and 2011

Key: **CIS** – Checklist Individual Strength; **FACIT-F** - Functional Assessment of Chronic Illness Therapy-Fatigue; **FIS**- Fatigue Impact Scale; **FQ** - Fatigue Questionnaire; **GSCL (fatigue)** - Short Form Giessen Subjective Complaints List; **IBDQ** – Inflammatory Bowel Disease Questionnaire; **MFI** - Multidimensional Fatigue Inventory; **PFS** - Piper Fatigue Scale; **SF-36** – Health Survey Short Form-36.

Appendix IV Primary research appraisal tool and data extraction for meta-synthesis of qualitative research

(Adapted from Paterson et al 2001) and Critical Appraisal Skills Programme (CASP) guidelines (www.casp-uk.net)

Assessment Criterion	Question	Consensus definition YES/NO/NS/NA*
Code: Reference: Chronic disease: Major construct/theory investigated: Methodological design: Sample size and characteristics: Data collection method: Major findings:		
Research design		
Problem statement	Statement of the phenomenon leads directly to the purpose of the study and the research question?	
Purpose of the research	Purpose clearly stated? Significance of the research problem clearly indicated? Is rationale for the study clearly stated?	
Research question	Explicitly expressed? Evidence of flow from the phenomenon?	
Identification of assumptions	Identification of assumptions, preconceptions, presuppositions of researcher?	
Identification of theoretical framework	Identification of theoretical framework? If 'yes', name framework or describe it Justification for the choice given? Clarification of the influence of the theoretical framework?	
Methodology	Does the chosen methodology fit with the purpose of the study?	
Researcher credentials	Documentation of researcher's discipline? If 'yes', name it, e.g. Nursing Any other pertinent information about the researcher, e.g. methodological or conceptual preference?	
Role of researcher	Non-research relationship of researcher to participants? Evidence that the researcher has considered the possibility of researcher bias or misinterpretation?	
Sampling		
Sampling strategy	Description of the type of sampling procedure? Description of the participants? Identification of inclusion criteria? Discussion of attrition in longitudinal study?	

Data gathering strategy(ies)	<p>Clear description of data gathering procedures?</p> <p>Does data collection fit with methodology?</p> <p>Are any tools (interview/focus group guidelines) provided?</p> <p>Description of gaining access?</p> <p>Discussion of time frame of data gathering?</p>	
Data analysis strategies	<p>Description of the method(s) used?</p> <p>Clear framework provided?</p> <p>Does data analysis method fit with methodology?</p> <p>Identification of categories or common elements or themes found and relationship between them?</p> <p>Is the analysis well supported by representative quotes/findings?</p>	
Findings	<p>How are findings presented?</p> <p>Is this consistent with methodology?</p> <p>Are findings a likely product of the study?</p>	
Conclusion, discussion, implications, suggestions for further research	<p>Identification of study limitations?</p> <p>Discussion pertains to all significant findings?</p> <p>Do the interpretive statements correspond with findings?</p> <p>Examination of the findings with existing literature?</p> <p>Clear indication of directions for future research?</p>	
Evidence of rigour	<p>Credibility</p> <p>Transferability</p> <p>Dependability</p> <p>Confirmability</p>	
Ethics	<p>Are ethical assurances, including evidence of participant consent, given?</p>	
Other considerations/ thoughts/ study limitations	<p>Does the study have any limitations? Are these addressed by authors?</p>	
Decision to include in meta-synthesis	<p>Yes</p> <p>No</p> <p>Undecided (explain below)</p>	

Appendix V Keys features of the studies included in meta-synthesis in chronic conditions

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
1.Glaus et al (1996) Switzerland and UK 2. Cancer (n 20) Healthy individuals (n 20) 3.Grounded theory	To explore fatigue in cancer patients and to compare experience with that of healthy individuals	Maintaining rapport and trust were considered important to keep the patients talking, and maintaining their psychological well-being,	Purposive sampling, patients selected weekly from inpatient oncology department, they had to meet selection criteria, healthy individuals found through personal contacts	Unstructured interview, with open questions, later interviews became more structured as the preliminary findings enabled questioning to be more focused, data collected Aug-Sept 1994 in patient group, data saturation achieved, length of interview 30-50 min, tape-recorded and transcribed by the researcher to become familiar with the data,	Subjects show no sign of 'stage fright', field notes were made to record special events – not stated what and how dealt with, patients interviewed in their room or researcher's office if there was a need for privacy	Hospital Ethics approval, and head of department, Oral consent from patients and healthy individuals, confidentiality assured, Previous knowledge and experience were subordinated as a 'hidden agenda', all interviews conducted by the same nurse researcher
1.Pearce & Richardson (1996) UK 2. Cancer (n 6) (1 died, and 1 was too weak to take part)	To understand and describe the meaning of fatigue for cancer patients	Researcher to use all senses to concentrate on the subject's experience, with appropriate feedback to	Purposive selection through liaison with the oncology nursing staff,	Broad open-ended questions, use of probing questions,	Attempt to avoid influencing the informant by asking broad open ended questions, field notes included observation and non-verbal data and	Verbal consent obtained after a full explanation of the study, telephone and letter contact made to arrange the interview,

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
this left just 4 participants 3. Phenomenology (not stated which, but interpretive)		convey support, empathy and awareness, the researcher sought the informants' constant clarification and validation of meaning to refine further their considerable insights into their experience of fatigue,			the context of the interviewee-interviewer relationship, subjective bias,	bracketing, checking and rechecking the data, field note documentation and self-reflection increased the researcher's ability to identify and control biases and distortion within the method,
1.Ream & Richardson (1997) UK 2. Cancer (n 9) COAD* (n 6) 3. Phenomenological approach (not stated which, but descriptive)	To gather in-depth descriptions of fatigue; Research questions: What are cancer and chronic obstructive pulmonary disease (COAD) patients' experiences of fatigue? What are their thoughts and feelings about it?	Researcher continuously reviewed the emerged themes for evidence of bias (How it was done is not stated),	Suitable out-patients (had fatigue and were able physically and emotionally to participate in the study) were identified under the direction of the medical and nursing staff involved in their care,	Individual semi-structured interviews, mainly at home, one chose to be interviewed in a private room in the Out-patient Dept, list of probes given, 25-45 min, tape-recorded and transcribed verbatim,	The study was susceptible to bias as it was collected by a single researcher using interviews as the primary method of data collection – this could have potential implications for the truthfulness, the researcher recorded relevant contextual field notes on completion of	The respondents were assigned pseudonyms to preserve their anonymity, to limit bias, the researcher's preconceptions of fatigue were documented prior to commencing the study (see list provided), these were reviewed=,

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
	The study aimed to gather in-depth descriptions of fatigue.				each interview, these data aided the understanding of the transcripts and supplemented the researcher's memory of the general ambience which was not captured o the recordings,	reflected upon and held in a abeyance (bracketed) throughout each interview, because truth is compromised when preconceptions influence data analysis, bracketing continued until analysis was complete, The truthfulness or credibility of the data was determined through performing member check, six participants assisted with member check and accepted the descriptions as their own,
1.Stuifbergen & Rogers (1997) USA 2. Multiple sclerosis	To elucidate the perceptual and behavioural manifestations of	Not discussed	Convenience sample, a combination of snowball and	Semi-structured interviews, with interview guide, the interview was a guided	Process notes completed by investigator, immediately after each interview to document	None discussed

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
(n 13) 3.Qualitative descriptive design (specific design not stated)	fatigue, perceived antecedents and management strategies		theoretical nonprobability sampling, purposive, theoretical sampling of informants to achieve diversity of the sample and maximum information about the phenomenon, volunteers recruited through notice about the study in a local newspaper for persons with MS, recruitment criteria,	purposeful conversation, ‘grand tour’ question to start, this allowed to establish what was important to participants, 1 st interview used to get informants to tell their own stories- how they viewed the experience of fatigue in their lives, 2 nd interview (within 2 or 3 weeks) was used to clarify transcribed data from the first interview (informant checking), to solicit more in-depth information, and to validate emergent categories and themes, 60-90 min interviews,	and describe the setting, general impressions, and nonverbal cues. Recruitment continued until data saturation,	
1.Magnusson et al (1999) Sweden 2. Cancer (n 15) 3.Grounded theory	To explore the experience of fatigue in cancer patients and to describe its	1 st researcher’ knowledge about fatigue and her long experience of working with cancer patients	Open sampling (patients identified by nurses on the ward) used initially, but became more	Unstructured, tape-recorded interview, interviews took place in an office at the hospital, conducted by the first author in the period of	Data collection and data analysis occur concurrently with constant comparative method, to achieve data saturation, aware of	Ethics approval granted, oral consent to participate,

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
	categories and dimensions	were used to confirm the respondents' statements and to assess the validity of the findings	strategic (theoretical sampling) to receive respondents of different ages and different medical diagnoses	May '97-Apr '98, transcribed verbatim by the author,	possible influence on the data collection, coding and analysis, Cannot be sure if nurses identified the most tired patients in order to protect them,	
1.Flensner et al (2003) Sweden 2. Multiple sclerosis (n 9) 3. Phenomenological approach (Husserl's philosophy)	To describe MS-related fatigue as lived by a group of individuals	Not discussed	Letter to local MS-group asking for volunteers, only those contactable by phone were included (n 9)	Interview lasting 1-1.5 hr, eight participants interviewed at home and one in the local MS-group room, , use of open-ended questions, tape-recorded and transcribed verbatim	Interviews carried out in private and in conversational form focussing on interviewees' experiences ,	Oral and written information about the study provided before the interview, informed signed consent, University Ethics Committee approved the study
1.Lindqvist et al (2004) Sweden 2. Cancer (n 4) 3. Phenomenological-hermeneutic approach (Ricoeur 1976)	To illuminate meanings of the phenomenon of fatigue as experienced by patients with cancer in palliative care	Not discussed	Six patients who expressed feelings of fatigue were ask by ward nurses to participate, however two were unable to take part due to a rapid decline in health,	Qualitative interviews, one of interview carried out in patient home, Feb-Mar 2001, lasted 40-105 min, taped-recorded, transcribed verbatim,	Not discussed	University Ethics Committee approved the study, verbal and written information given to participants, Transcriptions were validated against the recording by one researcher,

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
1.Porock & Juenger (2004) USA 2. Cancer (n 10) 3.Qualitative (specific design not stated)	To describe and explore the experience of fatigue in patients who had received biotherapy or bio-chemotherapy	Not discussed	Suitable patients were identified under the direction of medical and nursing staff in cancer centre, written information on the qualitative study provided and participants were encouraged to ask questions,	One time face-to-face semi-structured interview, approximately 1 hr interview, audio-recorded and transcribed by the research assistance,	Interviews collected by the research assistant at the patient bedside, implications not discussed,	Approval from the Health Sciences Institutional Review Board (HSIRB), participants already consented to participate in the larger study and HSIRB required only verbal consent for the qualitative part of the study, date time of the verbal consent kept on a log book,
1.Potter (2004) UK 2. Cancer (n 6) 3. Phenomenology Heidegger's hermeneutic circle	To explore and capture a detail description of the meaning and impact of fatigue in cancer patients	Heidegger allows the data generated by the participant to be focused with the experience of the researcher and placed in context, researcher is part of the process, researcher had experience of caring for cancer	Purposive sampling to recruit participants who are living the experience, participants were recruited from a population attending the local palliative day care unit, nurses were asked to identify potential	Individual semi-structured, tape-recorded interview, at home or a private room in the day hospice, open questions were used to focus on certain themes if participants did not naturally cover them,	The in-depth and the richness of the data collected usually allow the sample to remain small, A reflective diary was used to record the researcher's description and interpretation of the interviews – The themes were expanded on as each	Ethical approval obtained, the Husserlian tradition requires the researcher to 'bracket' or withhold their views and assumptions of the phenomena to allow unpolluted description of the experience – as researcher will

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
		patients suffering from fatigue,	participants with advanced cancer who expressed unprompted that they were suffering from fatigue, verbal and written information given to potential participants,		interview was completed,	always have some foreknowledge about phenomena this may not be possible, researcher kept reflective diary, the diary data were used at the analysis stage to enhance credibility
1.Gledhill (2005) France 2. Cancer (n 24) Healthy subjects* (n 24) 3. Grounded theory	To explore the underlying concepts and clarify definition of fatigue in patients with cancer and healthy subjects	Not discussed	Part of a larger research programme and followed translation and validation of a French version of Piper's Fatigue Scale, theoretical sampling, subjects recruited in outpatients or the wards,	Individual open-ended interview, audio-taped, data collection and analysis occur simultaneously,	Categories and concepts constructed and verified as research progressed	Ethical approval obtained,
1.Hewlett et al (2005) UK	To explore the experience of fatigue in patients	Not discussed	Patients were approached in outpatient clinic	One-to-one semi-structured interview, lasting 45 min, use of	Recruitment continued until no new data emerged,	Ethics approval obtained, data anonymised,

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
2.Rheumatoid arthritis (n 15) 3.Qualitative (specific design not stated)	with rheumatoid arthritis		and purposively selected according to selection criteria,	interview schedule and probing questions, audio-taped and transcribed verbatim,		
1.Olsson et al (2005) Sweden 2. Multiple sclerosis (n 10) 3.Phenomenological hermeneutic (Ricoeur, 1976)	To elucidate the meaning of fatigue as narrated by women with multiple sclerosis	Not discussed	Purposive sample, Recruitment was arranged through a hospital rehabilitation clinic, information about the study was given to the patients and the invitation to participate, a letter was sent then to information and obtain consent,	data collection took place in 2002, three women were interviewed at the hospital (separate room) and seven at home, personal tape-recorded interviews using narrative methodology were conducted, 40-60 min, transcribed verbatim,	Not discussed	Regional health ethics committee approved the study, women could withdraw at any time, confidentiality and anonymity were guaranteed,
1.Bennett et al (2007) Australia 2. Cancer (n 16) Chronic fatigue syndrome* (n12)	To understand the manifestations of fatigue in CRF and compare to CFS	Facilitator, to encourage participation	Nonprobability, purposive, consecutive outpatients, had to meet inclusion criteria	Focus group (3-6 participants /group) interview with open-ended questions, session continued until saturation achieved ,	Relaxed atmosphere, ground rules, no right or wrong answer, privacy and confidentiality, interactive process, data gleaned from one FG was used to inform the	Ethics approval, written informed consent, use of pseudonyms, two researchers facilitated FG, use of predetermined

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
3.Qualitative (specific design not stated)				audio recorded, transcribed verbatim	process for the subsequent group	framework for the sessions
1.Olson et al (2007) Canada 2. Cancer (n 27) 3.Ethoscience method	Research questions: 1. What behavioural patterns distinguish tiredness, fatigue, and exhaustion? 2. What are the similarities and differences between the behavioural patterns for tiredness, fatigue and exhaustion as reported by individuals? 3. What evidence is there that tiredness, fatigue and exhaustion are related to each other in a manner	Not discussed	Individuals meeting the selection criteria were identified by nursing staff employed at the data collection sites, research team contacted interested patients with more information	Ethno-science interview with open-ended questions, ½ hr recruitment interview and 1-3 study interviews lasting up to 1.5 hrs each, audio-taped and transcribed, Following transcription words that fit conceptual definitions of fatigue, tiredness and exhaustion were identified and placed on cards for card sorts (dyadic, triadic, Q-sort), card sort were conducted during the second interview, when finished patients were asked to name each pile of cards and identify similarities and differences between piles, following the	Participants readily discussed their experience of fatigue, thus to obtain additional data patients were asked to identify friends, family and nurses who had cared for them – implications of this not discussed,	Ethical approval granted, written consent,

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
	consistent with Stress Theory?			second interview segregates, sub-segregates and elements of Tiredness, Fatigue and Exhaustion were identified		
1.Wu & McSweeney (2007) USA 2. Cancer (n 10) 3. Phenomenological approach as developed by Husserl and Heidegger	To explore the meaning of fatigue from individual's perspective diagnosed with breast cancer	Not discussed	Criterion sampling from outpatient chemo infusion centre, inclusion criteria, participants recruited by using a display and personal invitation, patients self-identified themselves or were identified by the 1 st author with the help of clinic nurses, were recruited on the day of their chemo treatment	A personal interview, 6 patients also returned completed 2-week diaries, data collected by the 1 st author, Nov 2000- Feb 2001, audio-taped, semi-structured individual interviews, interview guide, 30-60 min, and 2-week daily fatigue diary keeping activity, the audio-tapes were transcribed prior to analysis,	Subjects were encouraged to speak spontaneously about their experience of fatigue,	Study approved by the Institutional Review Board, informed consent given (not stated verbal or written),

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
1.Mills & Young (2008) UK 2. Multiple sclerosis (n 40) 3. Mix-methods study with qualitative phase	To define the symptom of fatigue as experienced by patients with multiple sclerosis in terms of a common framework, First qualitative part aimed to derive the features of the definition of fatigue	Not discussed	Unselected outpatients, but some inclusion criteria stated (MS diagnosis and able to converse intelligibly in English, no other neurological disease),	Semi-structured interview, all interview collected by the 1 st author, tape-recorded and transcribed verbatim, 30-50 min, transcript length 2500-4500 words.	Interviewer was a doctor (neurologist) who was not involved in patient's care, spouse/partner could attend the interview with patient permission,	Local Ethics approval, all subjects gave written consent to take part in the study, All transcripts verified against the tape recording by the 1 st author, data anonymised,
1.Repping-Wuts et al (2008) The Netherlands 2.Rheumatoid arthritis (n 29) 3.Qualitative (specific design not stated)	To explore the experience of fatigue from the patients' perspective diagnosed with rheumatoid arthritis	Not discussed	Consecutive patients attending outpatient clinic were invited to participate in the study, selection criteria were set, experiencing fatigue was not a criterion for inclusion, recruited over the	Patients completed written questionnaires at home prior to their visit to the outpatient clinic, Interviews were conducted prior to or immediately after the appointment with a rheumatologist or a nurse specialist, 30-60 min, audio-taped, semi-structured, with a topic list, all interviews	In order to avoid influencing patients in advance, all patients were first exclusively invited to answer on the five topics in their own words, after extensively verbalising their experience, written list of concept, causes and consequences, based on literature were handed	Study protocol was presented to the local Ethics committee – the committee concluded that approval was not needed as medical treatment was not modified for this study and filling out questionnaires and being interviewed on

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			period of 4 months Jan-Apr 2006,	collected by the same researcher in a separate room in the outpatient, in order to standardise the interviews, each patient was asked the same questions in the same order, opportunity for additional comments was available at the end of the interview, field notes made to record special events,	over to help patients broaden their thoughts,	fatigue were not seen as burdensome, Patients were informed that all interviews would be anonymous and that the tapes would be destroyed after analysis,
1.Blaney & Lowe-Strong (2009) Northern Ireland 2. Multiple sclerosis (n 10) 3. Phenomenological approach (specific design not stated)	To explore and gain inside into the lived experience of the interaction between fatigue and communication	Facilitative, use of open, neutral questions and probes to elicit in-depth descriptions, to clarify meaning, give examples	Response to advertisement, had to meet inclusion criteria	In-depth interview, audio recorded, interview 1: completion of self-report fatigue questioner and interview; Interview 2: transcripts and meaning units verified by participants	Nine participants interviewed at home, one at work in a private office, participant viewed as expert with their unique experience	Ethics approval, written consent, participants verifying interview transcripts and meaning units
1.Nikolaus et al (2010) The Netherlands 2.Rheumatoid arthritis (n 31)	To gain further insight into the experience of fatigue and whether fatigue	Not discussed	Consecutive outpatients diagnosed with RA min 2 years, interested patients	Hierarchical interview scheme comprising eight main topics,	Not discussed	First author collected al the interviews,

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
3.Qualitative (specific design not stated)	experience differs between patients with rheumatoid arthritis		received information letter about the study,			
1.Tsai et al (2010) Taiwan 2. Cancer (n 15) 3.Qualitative (specific design not stated)	To explore fatigue experience in older women with breast cancer	During the interview, women were encourage to express their feelings and their experience, the first author collected all the data,	Purposive sampling, selection criteria, oncology outpatient, in a teaching hospital, possible participants were approached after their outpatient treatment and given written information explaining the study,	In-depth semi-structured interviews with interview guide, data collected Nov 2006-March 2007, 30 min interview, in the private room in hospital or in place of residence, whichever was the most comfortable and relaxing for participants, data collection Nov 2006 – Mar 2007, approx. 60 min interviews, audio-taped and transcribed verbatim immediately after the interview	Researchers had two weeks of oncology outpatient field observations in the hospital to familiarise themselves with the treatment environment and the possible participants, all data collected by 1 st author for consistency and until data saturation achieved, interviewer recorded non-verbal behaviours, any special events that occurred and thoughts derived from the interview	Ethics approval obtained, written consent, protection of identity, confidentiality, emotional support provided with sensitive issues, participants gave their permission to be audio-recorded, Trustworthiness was established by using Lincoln & Guba (1985) criteria , open-ended interviews were used to verify participants' responses, and participants were asked to validate findings to establish

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
						credibility (in study background it was stated that many Taiwanese women are illiterate, it is not clear in any of the participants were unable to read),
1.Pongthavornkamol et al 2012 Thailand 2. Cancer (n 10) 3.Ethnoscience	To learn more about how Thai adults with cancer describe fatigue to compare these descriptions with the previously reported in a study of Canadian adults with cancer, two questions were posed to address both parts of the aims,	Not discussed	Individuals collected from tertiary public hospital, who met eligibility criteria, to maximise variability the sample was stratified using tiredness scale, and other scales,	Individual interviews 2-3 times, process replicating Canadian study of Q-cards sorting and naming each group, till data saturation, PhD student collected all interviews, tape-recorded and transcribed, data were analysed as they were collected, creation of Q-cards and sort on 2 nd and 3 rd interview,	Data obtained early in the study was used to inform conversations with participants later in the study,	Ethics approval granted, written consent, Rigor was assessed by using the verification strategies developed by Morse et al 2002,as it facilitates the ongoing assessment of reliability and validity as the study progresses and the opportunity to correct any error while the study is ongoing, transcripts

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
						were compared to tape recording to assure accuracy, strategies used were: methodological coherence, appropriateness of the sample, concurrent data collection and analysis, theoretical thinking, an theory development, interviews conducted and first transcribed in Thai, and then translated to English
1.Siegel et al (2012) USA 2. Cancer (n 35) 3.Qualitative	To examine the attributions for fatigue and to examine symptom interpretations and remedial coping responses of older cancer patients	Not discussed	Convenience sample, Patients were recruited as part of the larger study, in a university-based cancer centre, eligible patients were identified by their treating	Qualitative in-depth interviews, data collected over 16 months period, each interview lasted approx. 2.5 hrs (first 20 min sociodemographic questionnaire 20 min and then over 2 hrs qualitative interview,	The study also interviewed the patients' informal caregiver (data not presented in this paper), patients initially were asked to report all the symptoms they had experienced in the past 30 days, then to identify	Study was reviewed and approved by the university and the cancer centre

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
			oncologist or/and nurses or review of their medical records, selection criteria used,	one male and four female interviewers involved and patients were given a preference, 90% of interviews took place at home, and the rest at the authors; office near the cancer centre. Patients and caregivers interviewed separately, Interview guide used,	and discuss two symptoms in depth: first the most difficult symptom they had to contend with, and second the symptom with the most recent onset. After pain, fatigue was the second most frequently reported and discussed symptom in the study; The full sample of 80 patients were interviewed, but only the 55 years old and over were included in this data analysis, \$25 honorarium for completing the interview,	
1.Spichiger et al (2012) Switzerland 2. Cancer (n 19) 3.Grounded theory	To explore cancer chemotherapy recipients' current perspectives regarding fatigue	Not discussed	Oncology outpatient, part of the larger study, selection criteria used,	Patients interviewed after their third chemotherapy, in separate room at the outpatient clinic, two trained research	The research assistants also prompted participants to explore interesting topics as fully as possible,	Study was approved by the ethics committee, Written informed consent obtained,

1.Source 2.Condition/Sample 3.Methodology	Research question	Role of researcher	Sampling procedure	Data collection	Influence of data collection process on research findings	Rigour/ Ethics
				assistants (oncology nurses) conducted the interviews following a guide, 30 -65 min, use of open-ended questions to elicit accounts of fatigue experience, tape-recorded, transcribed verbatim,		

Appendix VI Data extracted from qualitative studies on fatigue in chronic conditions

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
Glaus et al (1996) Switzerland & UK	1. Cancer 2. Grounded theory 3. Theory generation	3 main categories with 16 themes, Linguistic analysis, percentages, figures, pie charts	1. Physical sensation of tiredness (59% of all themes): decreased physical performance (18/20), weakness/no strength (17/20), unusual need for sleep (6/20), unusually tired/feeling worn-out (18/20), unusual need for rest (15/20); 2. Affective sensation of tiredness (29% of all themes): decreased motivation (7/20), need to force oneself to overcome inactivity (5/20), no energy (5/20), sadness (11/20), anxiety (4/20), no fighting spirit (4/20); 3. Cognitive sensation of tiredness (12% of all themes): lack of concentration (4/20), problems in thinking (4/20), mental tiredness (4/20), sleeping problems at night (3/20), malaise (2/20)	Fatigue categorised into physical, affective and cognitive expressions; In cancer patients fatigue involved decreased physical performance, extreme, unusual tiredness, weakness and unusual need for rest;
Pearce & Richardson (1996) UK	1. Cancer 2. Phenomenology (not stated which, but interpretive) 3. None stated (Human experience as its lived)	5 themes	1. The nature of fatigue: difficult to define and explain, a drain on energy, lethargy, chronic, unpredictable, 2. Causes of fatigue: cancer process, treatment (chemotherapy, radiotherapy), pain, loss of appetite, nausea, stress, 3. Consequences of fatigue: depression, low mood, abandoning treatment, abandoning hope, life alterations or giving up, sense of loss, alterations or loss of employment, perceived loss of function, isolation, impact on family life and roles, being left out <i>'life goes without me'</i> , <i>'I'm obviously not the man I was'</i> 4. Strategies for coping with fatigue: adjustment (reduction in activities), attitude and acceptance, making sense, denial, avoidance of attempting to feel in control, extensive use of rest and relaxation <i>'I give in to it'</i> , <i>'you eat and you've got clean clothes'</i> , social support, emotional support, delegation, energy conservation, 5. The trajectory of fatigue: placed on the trajectory of cancer illness, pre-diagnosis, surgery, radiotherapy, chemotherapy (produced the greatest intensity of fatigue), post-treatment fatigue was less intensive,	There is a shared and individual experience of fatigue incorporating the nature of fatigue, causes, consequences, strategies for coping, and the trajectory of the fatigue experience;

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
Ream & Richardson (1997) UK	1. Cancer 2. Phenomenological approach (not stated which, but descriptive) 3. None stated (Subjective everyday experience)	9 themes (only 5- textural themes presented, structural themes not presented in this paper)	<p>1. The physical sensation embodied in fatigue: 'drained' of energy, exhaustion, aching (notably in lower limb), malaise, 'flu' like symptoms, uncomfortable feeling, cyclical pattern of fatigue,</p> <p>2. The mental sensations embodied in fatigue: poor concentration, lack of get up and go, reduced 'zest for life', 'mental haze' (when on chemo),</p> <p>3. The impact of fatigue on everyday functioning: limitations on everyday life, physical deficit, poor concentration, deterred from their normal social life and pastimes, low motivation, reduced pace of activities or abandoning them,</p> <p>4. The emotional feelings evoked by fatigue: being upset, increased reliance on others, low confidence, frustrated, low mood, downhearted, low self-esteem, grieving for the person that had been and the life that they had enjoyed prior illness and fatigue, 'why can't I be me again',</p> <p>5. The impact of fatigue on perceived control: unpredictable, difficult to control, in the 'lap of the gods', not in control, overpowering, overwhelming, failing to stay awake and active, unable to plan, lived for the short-term, day-by-day, feeling of insecurity,</p> <p>6. The impact of emotions on the management of fatigue;</p> <p>7. The importance of recognising and understanding fatigue;</p> <p>8. The significance of setting and reaching goals;</p> <p>9. The effectiveness of self-care in the alleviation of fatigue;</p> <p>Only the first five themes relate to the experience of fatigue itself (the textural themes), the final four themes are concerned with individuals' capacity to manage their fatigue (the structural themes). Only the textural themes are presented in the paper.</p>	<p>Fatigue depict as a complex phenomenon;</p> <p>Physical and mental sensations are embodied in fatigue;</p> <p>Fatigue impacts on everyday functioning;</p> <p>Fatigue impact and the emotional feelings evoked by fatigue impacts on perceived control;</p>
Stuifbergen & Rogers (1997) USA	1. MS 2. Qualitative descriptive design	4 broad areas (themes) with 5, 3, 4 and 3 subthemes	<p>1. The experience of fatigue: fatigue as an ever-present ongoing experience - deep fatigue; pervasive impact of fatigue on life - imposed limitations on life, influenced every decision regarding activities at work, home and play, 'fatigue just rules my life or tries to'; exacerbation of symptoms with</p>	<p>Fatigue was ever-present, had pervasive impact on life;</p> <p>The exacerbation of MS symptoms increased fatigue;</p>

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
	(specific design not stated) 3. None stated	each respectively	<p>increasing fatigue – weakness, loss of balance, emotional irritability, cognitive difficulty, impaired memory, attention and concentration, emotional changes crying, screaming at kids, emotionally exhausted, <i>‘like being in a dream’</i>, <i>loss of judgement and/or perception</i>, difficulty to respond appropriately harder to stay engaged; fatigue as paralysing force – powerless to perform activities; the undertow effect of severe fatigue – energy impoverishment ;</p> <p>2. Antecedent factors of fatigue: lifestyle patterns – physical exertion, trying to accomplish too many tasks in one day, poor nutrition, alcohol intake, lack of rest and sleep; environmental factors – heat, direct intense sunlight, humidity, cold; perceived stress – psychological stress related to family, work, socioeconomic, and other emotionally laden problems, <i>‘stress can really make me feel tired’</i>;</p> <p>3. Self-care strategies to manage fatigue: energy conservation – strategies used to reduce energy consumption (do less-physically and emotionally, help from others- difficult strategy to learn, and work smart – maximise performance or accomplish valued activities and minimise energy expenditure); recharge efforts – strategies to restore physical energy and/or attentional ability (diversional activities – listening to music, light reading, talking on the phone with friends), rest – rest was planned and necessary cessation of physical activity, napping and sleeping, sitting down, propping one’s feet up; medications – to promote sleep, or stimulants e.g. caffeine to improve energy levels during the day); enhancing resistance to fatigue – (to increase stamina) physical activities, exercise, nutritional strategies (well balanced meals, use of dietary supplements), and psychological approaches (maintenance of a positive attitude and seeing fatigue as inconvenience , rather than force driving one’s life choices); temperature control – staying cool, get cool after over-heating;</p> <p>4. Influences on selection and initiation of self-care strategies: suggestions from friends, family and others with MS – use of wheelchair to conserve</p>	Self-care strategies included energy conservation, recharge efforts, enhancing resistance to fatigue, and temperature control;

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
			energy, keeping life simple, taking acetaminophen before exercise, very few learned any practical self-care strategies for dealing with fatigue from HCPs, even if medication for managing fatigue existed HCPs were very reluctant to prescribe it; ideas gleaned from publications – strategies on how to live with MS, organising your life, advice from MS Society Newsletter ; self-discovery – self-reflection, trial and error (to come up with your own solution)	
Magnusson et al (1999) Sweden	1. Cancer 2. Grounded theory 3. None stated (Understanding of the concept of fatigue)	2 themes with 3 categories and 11 dimensions; Figure for the process of fatigue, tables	Theme 1: the categories, dimensions and qualities of fatigue: 1. Experience of fatigue: loss (of energy, strength, control, condition, pace, initiative ability, co-ordination, well-being, and sociability) , need (to be left alone), malaise (notions of cold, pain, alterations in pulse, or symptoms described in general terms as those connected with influenza), psychological stress (anxiety, feelings of emptiness, uncertainty for their future, insecurity, frustration faced with a perceived inability to influence their situation), emotional affection (feelings of dejection. sullenness or sadness, loss of patience), abnormal weakness (feebleness, tremors, vertigo, difficulties in remaining upright, to lift one's legs, or move, feelings of heaviness ' <i>feet stuck in concrete</i> ', tired eyes, or difficulties in concentrating), difficulty in taking the initiative (morning inertia, loss of interest in any kind of activity, general passivity, listlessness, and sluggishness); 2. Consequences of fatigue: social limitation (loss of former social contacts, inability to create new ones, avoidance pleasurable activities, contacts with people less frequent, cancelled social events), affected self-esteem (feeling worthless, insecure, or useless as they could not maintain the same physical or mental pace as others), affected quality of life (negative limitations in people's lives, altered and deteriorated quality of life); 3. Actions: coping by resorting to various kinds of activities amounting to self-help (reading, listening to music, cooking, doing crosswords, lying down or taking a nap), physical activities (walking was most frequent),	Fatigue illustrated as a process, described by metaphors; Fatigue described from more than one dimension, multidimensional symptom; Instead of expressing the experience of fatigue, the consequences of fatigue or actions due to consequences were presented

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
			<p>planning and preparing both physically and mentally; accepting fatigue and learning to cope with it was important t a cognitive level, trying to reduce the feelings that fatigue is a problem (was difficult as fatigue caused great frustration),</p> <p>Theme 2: the words used by participants to describe fatigue: listless, sluggish, faint, despondent, apathetic, tired, slack, indifferent, and paralysing fatigue. <i>'My legs felt like spaghetti'</i>.</p> <p>Concept of fatigue may be understood as a process consisting of experiences of fatigue leading to consequences resulting in actions.</p>	
Flensner et al (2003) Sweden	<p>1. MS</p> <p>2. Phenomenological approach (Husserl's philosophy)</p> <p>3. The empirical phenomenological psychological method (Karlsson 1995)</p>	<p>2 levels of analysis:</p> <p>2 themes,</p> <p>10 sub-themes</p>	<p>Level 1: A situational structure of MS-related fatigue – one description of the noetic side (description of one participant's – Gabriella - experience of fatigue) – discharging a battery of energy, happens very quickly from one minute to another, paralysing power, invades her whole body at any point in time, does not trust her body, which betrays her, feelings of uncertainty emerge. Hard to move, she depends on help, lives very restrictive life.</p> <p>Level 2: A general meaning structure of MS-related fatigue – the noematic side (with 2 themes and 6 & 4 sub-themes each respectively)</p> <p>1. Themes of non-constructive perceptions of fatigue:</p> <ul style="list-style-type: none"> - time-consuming and all absorbing: fatigue always present, living in uncertainty, thinking about fatigue as occurring at any time, had to plan everything in advance, could not manage daily activities without resting, vicious circle, thinking about fatigue could bring the onset of fatigue, MS symptoms became worse as a result of fatigue, and fatigue became worse of other MS symptoms, had to avoid stressful situations, did things in advance in a calm and methodological way, this was also perceived time consuming, - involvement of the body: MS-related fatigue was perceived in the whole body or part of it, fatigue did not feel natural and could not be taken for granted, body felt heavy, painful as if hard work was done or numbed, dead and not awake, or as if part of it was gone, use of metaphors ('a packet', 'legs as stumps', participants felt betrayed when fatigue invaded the body, 	<p>Fatigue is time-consuming and all absorbing, involving the body and the whole human being;</p> <p>Non-constructive perceptions is expressed in terms of energy loss, emotional afflictions, dependency and restrictions of life in general;</p> <p>Constructive perceptions involves a desire to accept life and strive for a better situation;</p>

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
			<p>body hard to control and could not be trusted, perception of lower cognitive ability when fatigued, difficulties in concentrating and withstanding any disturbing sound, difficulty thinking and problem solving,</p> <ul style="list-style-type: none"> - loss of energy: fatigue totally different from common exhaustion (e.g. after physical activity), happen very rapidly, always have less energy and strength, totally drained of energy , - emotional perceptions: being worthless, lowered sense of self-worth, despair, sadness and sorrow, '<i>a pitiful person</i>', perception of shame, having bad conscience and guilt for not managing to continue with work, experience of loss of ability in front of others, being misunderstood, perception of shame, anger, being mistaken by others for being drunk, some chose to stay indoors, - dependency: being trapped in the sense of needing help from others, need for immediate rest, sense that one had to live a very structured life, fillings of being exposed, others did not always understand their needs, surrounding environment, the temperature (hot temp or low air-pressure or thunderstorm) and the climate, - restrictions of life: change of roles within family, working and social life , involuntary isolation, life become boring , <p>2. Themes of constructive perceptions:</p> <ul style="list-style-type: none"> - desire for acceptance of life: activation of a fighting spirit, struggle to maintain their abilities, facing up to facts, accepting and living with one's limits and boundaries, they did not push themselves to their limit so they could still feel well, focus on what one can manage instead of and what they can't, perceived sense of happiness and contentment in managing small things, maintain a positive view of life, knowledge about disease and fatigue helped them further, to take one day at the time, prioritise pleasant, enjoyable and meaningful things (meet with friends, experience fellowship, friendship and pleasure, interests groups, choir, drawing, painting), have a feeling of satisfaction, joy and happiness, 	

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
			<ul style="list-style-type: none"> - desire for a structured daily living: advanced planning, following a rigid pattern, time to do things and time to rest, avoiding feelings of stress, doing things in advance, allocating more time so to do things in a calm way, plan what to eat to feel well, - means of assistance becoming body-as-lived: some perceived their means of assistance as a natural part of their lives, allowing them to live a more normal life '<i>extended arms and hands</i>', - typological structures: variations and meanings of fatigue were found in the individuals' situations 	
Lindqvist et al (2004) Sweden	1. Cancer 2. Phenomenological-hermeneutic approach 3. Ricoeur philosophy to understand the ways of being in the world	Two levels of analysis: naive understanding and structural analysis with 2 themes and 5 sub-themes; comprehensive understanding and reflections (discussion and comparison with broader literature)	<p>Level 1: naive understanding – fatigue seem to be diffuse and intangible, word fatigue seldom used, but rather a physical experience of exhaustion, lack of physical strength and weakness, complex relationship between cancer, fatigue and death, body puts a stop to things, affecting daily life, and preventing the life one wants to live. Three paradoxes emerged: 1) most participants had not thought about or reflected on fatigue, even though it was described as a hindrance, it had not been understood as a hindrance even though it was described as one 2) to exercise and be active was described as perhaps the most significant strategy for counteracting fatigue, if only one exercised, things would improve, but they had no strength and thus cannot exercise and seems that it is oneself who is to blame, 3) hope and expectations are mixed, participants express hope that the fatigue will diminish or not worsen, but at the same time doubt that this is realistic as the body says otherwise;</p> <p>Level 2: Structural analysis</p> <p>1. Being unable to live the life you want to live:</p> <ul style="list-style-type: none"> - being trapped in a failing body – body can no longer be trusted and relied on, lack of strength and exhaustion, things previously taken for granted are now difficult, difficult to plan ahead, negative feelings of disappointment, frustration, humiliation, irritation, discomfort, uncertainty, fear, 	<p>Meaning of fatigue connected with incurable cancer is a lived bodily experience of approaching death;</p> <p>This explains paradoxes such as struggling in vain against fatigue and hoping to overcome fatigue but expecting failure;</p> <p>The paradoxes represent a struggle between body and mind, between bodily experience and intellectual understanding, and impacts on how fatigue should be communicated to patients;</p>

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
			<ul style="list-style-type: none"> - becoming dependent on and a burden to others: unable to cope with household chores, needing help with personal hygiene, expect fatigue to increase in the future and make them more dependent, feelings of becoming a burden on those closest, - not having the strength to be with others: fatigue makes being in company difficult and is a cause of a risk of isolation, <p>2. Longing for a healthy life:</p> <ul style="list-style-type: none"> - struggling in vain against fatigue: trying to fight fatigue, attempting to improve strength and stamina through physical exercise, feeling of uncertainty and hopelessness, strategy alternates between fighting against and accepting fatigue, - hoping, but not expecting, to overcome fatigue: paradox in hope and expectations, wishes and hopes meet feelings and intellect, optimism is expressed but expectations a more gloomy view of the future, <p>Comprehensive understanding – discussion</p>	
Porock & Juenger (2004) USA	1. Cancer 2. Qualitative (specific design not stated) 3. None stated	4 themes	1. Life-disrupting severity of fatigue: physical, mental, social aspects of life, inability to continue working, and to maintain the ‘normal’ life, ‘ <i>stayed bedridden</i> ’, ‘ <i>obliterated</i> ’, nutritional intake was altered, overwhelming decrease in appetite, loss of concentration, motivation, feelings of boredom, could not complete constructive or meaningful tasks, ‘ <i>I was like a zombie</i> ’, delicate balance between needing support and needing to be left alone, 2. Altered sleep patterns: disrupted night sleep, daytime naps (20 min – many hours), going to bed earlier (e.g. 6.00 pm), 3. Informational needs met: patients received information about fatigue e.g. video, talking with the nurse /physician, 4. Advice for other patients: be strong and go with the flow, there is nothing you can do to stop it or prevent it, it must be endured,	The strongest meaningful advice from the participants was to ‘be strong and go with the flow’; Boredom associated with cognitive fatigue and inability to accomplish work and other tasks;
Potter (2004)	1. Cancer	5 themes and 18 categories,	1. Physical consequences of fatigue: impact on daily activities/effects on quality of life – everyday tasks such as personal hygiene, walking, caring	Meaning of fatigue was intertwined with the process of

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
UK	2. Phenomenology, Heidegger's hermeneutic circle 3. None stated	Table and figure – The interconnectedness of the themes	for their home, cooking and eating had become uphill struggle; physical sensations/descriptions – fatigue difficult to describe, use of metaphors, intangible, complex phenomenon, unpredictable, changes in energy levels, difficult to plan, energy levels used as a barometer to gauge where the illness process, tiredness/energy levels, other symptom burden, causes of fatigue – breathlessness, anaemia, cancer, treatment, ; 2. Psychological consequences of fatigue: poor memory/concentration, struggling to accomplish tasks, stress and worry, uncertainty/unpredictability/loss of future, striving for normality, loss of independence, feelings of isolation and loneliness; 3. Social consequences of fatigue: family dynamics changed, change in roles, effects on family/carer, heavy burden on others, social isolation, frustration, loss of pleasurable activity; loss of role within the family, 4. Spiritual consequences of fatigue: hope/hopelessness, fatigue related to dying, being out of control, difficulty in accepting situation/need for assistance, fatigue described in relation to cancer and thought of dying; 5. Struggling to cope with fatigue: helpful/unhelpful coping mechanisms; pacing, resting, delegating, prioritising (but there was little evidence of effectiveness of these methods)	adjusting to living with a terminal illness and ultimately death, and it was impossible to separate the two; Coping strategies that would normally be of use to fatigued individuals were shown to have little /no benefit; Sensitive communication about fatigue and its meaning to the patient may assist adjustment and generate hope;
Gledhill (2005) France	1. Cancer 2. Grounded theory 3. Theory generation	7 themes, Percentages & mean, Model of interrelationship between symptoms (physical, psychological, social),	1. Physical manifestation of fatigue (35% of all themes): lack of stamina (22/24), increased time spent resting and sleeping than before illness (21/24), decreased energy (19/24), weakness/lack of strength (17/24), slowing down in physical activities (15/24), decreased in sexual activities (11/24); 2. Affective manifestations of fatigue (41% of all themes): low spirits (20/24), lack of motivation (20/24), anxiety, anxious-depressive trait (18/24), mood swings, irritability, anger, aggressiveness, impatience, frustration (17/24), need to force oneself to engage in activity (14/24), intrusive thoughts (13/24), lack of courage, will power (12/24), lack of vitality, vigour (10/24);	Intensity, variability, duration and temporality of fatigue is more severe in patient group than in healthy subjects; Fatigue has three major dimensions, physical, affective and cognitive; Fatigue related distress was identified in the patient group; The linguistic descriptions of fatigue confirmed differing

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
		Model for evolution of fatigue	<p>3. Cognitive manifestations of fatigue (24% of all themes): difficulty in concentrating (16/24), difficulty in resolving problems, reasoning (16/24), lack of interest in people, activities, information, environment (12/24), somnolence during the day (11/24), problems in memorisation, recall (10/24), lack of creativity (6/24), lack of lucidity (3/24);</p> <p>4. Major themes of distress revealed through the different metaphors, images and expressions used by participants: helplessness (15/24), threatening experience (14/24), worn out (10/24), isolation (9/24), culpability (8/24), loss of identity (5/24), loss of life's meaning (5/24), dependence (4/24)</p> <p>5. The fatigue cycle in cancer patients: heavy limbs, drooping head or shoulders, whole body fatigue, both mental and physical, use of metaphors to describe fatigue,</p> <p>6. Distress caused by cancer-related fatigue</p> <p>7. Symptoms implicated by patients in the development of CRF: pain, sleep disturbance, decreased appetite, weight loss, nausea, vomiting, somnolence and dyspnoea, were the most frequently reported symptoms</p>	<p>perceptions of fatigue between patients and healthy individuals and a heightened concerns for the negative aspects of fatigue and suffering among patients;</p> <p>Individuals respond differently to fatigue;</p>
Hewlett et al (2005) UK	<p>1. RA</p> <p>2. Qualitative (specific design not stated)</p> <p>3. None stated</p>	3 themes, Figure of the relationship between themes, categories and concepts	<p>1. Overwhelming and different from normal tiredness ('wipeout'): physical – heaviness, overwhelming, draining, no energy, weary, flu-like; cognitive – motivation; emotional – tearful; not normal – not earned, unresolving; triggers – everyday tasks, doing too much; attributed causes – RA/pain, working harder, tasks take longer, sleep; Fatigue presented as severe and overwhelming, different from normal tiredness because it is extreme, often not earned and unresolving;</p> <p>2. Consequences permeate every sphere of life: activities – work, household, leisure; life on hold – can't plan; role – family, social; relationships – strained; emotions – frustration, irritable, self-esteem, resentment;</p> <p>3. self-management is variable and professional support is rare ('<i>You don't know what to do</i>'): self-management – attitude, pace, rest, variable success</p>	<p>There are physical, cognitive and emotional components of fatigue with far-reaching effects on physical activities, emotions, relationships, social and family roles;</p> <p>Participants used self-management strategies but with limited success, and they had negative views on the management of fatigue;</p> <p>Most did not discuss fatigue with clinicians but when they did, they felt it was ignored;</p>

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
Olsson et al (2005) Sweden	1. MS 2. Phenomenological hermeneutic (Ricoeur, 1976) 3. None stated	2 levels of analysis: level 1 - naive understanding Level 2 – comprehensive understanding and reflections on findings	Level 1: naive understanding 1. Experiencing the body as a barrier: a feeling of having a heavy body; a feeling of having the will but not the ability; a feeling of saving strength and needing to rest – need to slow down, to rest, plan daily activities, fatigue does not disappear after sleep; 2. Experiencing a different absence: an unusual and invisible feeling – never disappear and appear as a sudden feeling, swimming sensation, dizziness, feeling like body was spinning, nausea, impossible to stand upright, brain was not totally clear, problems walking, fatigue is different than tiredness before illness; a feeling of being absent – feeling of being split in two parts (part was participating and part was just watching), feeling of being anaesthetised, problem making sense of things around, problem participating during conversation, lack of concentration, Level 2: comprehensive understanding and reflections on the findings: living with a body as a barrier, feeling of ‘being absent’ in an usual way, and experiencing the surrounding world as unreachable.	The body was experienced as a barrier and an enemy of survival, fatigue gave rise to an experience of being absent; Fatigue led to a feeling of not being able to participate in the surrounding world; The feeling of being an outsider and lacking the ability as a healthy person interpreted as a form of suffering;
Bennett et al (2007) Australia	1. Cancer 2. Qualitative (specific design not stated) 3. None stated	4 categories of symptoms, 3 categories of behavioural impact, Language describing fatigue, Model: characteristics of fatigue	First level analysis sorted into four categories: 1. Fatigue: ‘abnormal tiredness’ - implying exaggerated fatigue after activity; ‘lack of energy’ – implying fatigue at rest; ‘unrefreshing sleep’ – awakening from sleep without renewed energy; 2. Neurological impairment: ‘memory’ – particularly short-term memory; ‘attention’ – inability to sustain mental activity; ‘verbal fluency’ – sense of increased hesitancy in finding the words and feeling ‘lost for words’ 3. Mood disturbance: feelings of ‘sadness’, ‘frustration’, and ‘worry’; 4. Miscellaneous symptoms: symptoms associated with other conditions such as menopause, migraine headaches; Second categorisation – three categories of impact of fatigue: 1. Physical consequences: inability to function at work, inability to function at home – ‘I can only do a handful of things’;	Patients suffered disabling behavioural consequences of the symptom complex;

Study	1. Condition 2.Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
			<p>2.Psychological consequences : emotional, behavioural – ‘worrying that something had gone wrong’ , ‘in fear all the time’, ‘I feel this need to cry’;</p> <p>3.Social consequences: workplace, home – ‘I feel I can only cope with going to work and not doing all the other things that I did before’;</p> <p>Language describing fatigue: ‘I am very tired’, ‘ my brain’s gone’, ‘I have no energy’, ‘now I’m lost for the word’, I lose concentration, ‘I seem more absent-minded’, ‘I can’t fully concentrate on anything’</p>	
Olson et al (2007) Canada	1.Cancer 2. Ethoscience method 3. Adaptation model, Stress theory	3 domains, 2 segregates, and 5 sub-segregates, Figures: Fatigue adaptation model, and Moving between tiredness, fatigue, and exhaustion	<p>1.Three domains: tiredness, fatigue, exhaustion;</p> <p>2.Two segregates for each domain: mind, and body;</p> <p>3.Sub-segregates for each segregates: Mind – emotion, and thinking; Body – muscles, how the body feels, and interactions with others</p> <p>- tiredness: short tempered, edgy, forgetful, not sharp mentally, weak, heavy, don’t have the strength, draggy, worn out, can do usual activities;</p> <p>- fatigue: don’t have the get up and go , can’t concentrate, can’t follow through, spaghetti legs, can’t support my body, don’t move as fast, reflexes aren’t as good, it’s an effort to get my muscles to move, nausea, heart pounding, lightheaded, out of breath, off-balance, fall asleep on the spot, have to push myself to do things;</p> <p>- exhaustion: completely drained, confused, when it’s gone, it’s gone, body won’t cooperate, can’t move, dead tired, like somebody flipped a switch, don’t have energy, feel like you have to lie down, need to rest but can’t sleep, no desire but to sit and be quiet;</p>	Although tiredness, fatigue and exhaustion are all manifested by the same 5 attributes (changes in emotional, cognitive, muscular function, decreasing control over body processes and decreased social interaction) the qualitative differences in the manifestations support the assertion that they are distinct states;
Wu & McSweeney (2007) USA	1.Cancer 2. Phenomenological approach as developed by Husserl and Heidegger	6 themes, and several subthemes	<p>1.Different fatigue (than that experienced before illness), ‘<i>so much more than being tired</i>’,</p> <p>2.Physical sensations: ‘<i>listless</i>’, ‘<i>drained body</i>’, ‘<i>energy had been zapped out of me</i>’, overwhelming, non-stop, unrelieved by rest, unable to sleep; the object body – disrupted unity of body and self, ‘<i>my mind says get up and do something, and my body says, no, you can’t move</i>’, the self either attempts to control the body, or the self is controlled by the body,</p>	Fatigue described as much more than just being tired; Inability to anticipate the scope of fatigue and lack of awareness of strategies to combat fatigue was distressing;

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
	3. Embodiment and self-body relation		<p>3. I cannot... (fighter, surrender) – patients live in the world of '<i>I cannot</i>' instead of '<i>I can</i>', incapacity, loss of control, can't meet expectations; fighter – people exercise their will to master their fatigued body and retain the sense of integrity and the feeling of not being controlled by the illness; surrender – people may simply give up control when the body is unable to meet the demands or expectations,</p> <p>4. Emotional sensations: attempt to control the body during the breakdown of self-body unity, re-unification: harmony of lived body and object body (re-unification of self and body assumes a new form): reasoning; support (friend, family members, religion); the talk between self and body (body speak unfamiliar language and self must learn how to perceive and interpret the body language);</p> <p>5. Gaining the sense of control (the self attempts to control the body); (new capacity of understanding the body, developing new ways to deal with their fatigue through experiential learning, setting achievable goals, rewards to regain a sense of control, use of distraction, pacing, prioritising, planning ahead, knowing what to expect can regain sense of control);</p> <p>reflection/meaning – negative meaning of fatigue experienced as a limitation of the body, positive meaning as an expression of the body's own purpose, embodied meaning of illness emerge that help overcome the opposition of body and mind,</p> <p>6. Fatigue as holistic experience: fatigue impacts on all aspects of life,</p>	Various individual strategies, based on personal experience, were developed to regain a sense of control;
Mills & Young (2008) UK	1. MS 2. Mixed-methods study with qualitative phase 3. None stated	4 main headings, 6 sections of the framework with 5 sub-sections within section one, 46 themes and	1. Somantics of fatigue: use of words (tiredness, sleepiness and sleeping, a need to rest with or without sleep, weariness, pure muscle weakness, having no motivation, can't be bothered, being shattered or exhausted, having no energy, being drained of energy, use of metaphors of recharging/discharging a battery, being 'zonked', wiped out, wilted lettuce, cognitive problems of poor concentration, being drugged, memory problems, ataxia or in-coordination;	Despite variance across patients, fatigue could be described within the derived themes and framework; Fatigue could be defined as reversible motor and cognitive impairment, with reduced motivation and desire to rest;

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
		related descriptions, prevalence for each theme presented in %; 5 grouped themes with prevalence presented in % for each theme; tables and % for different features of fatigue	<p>2. Symptom framework: a) clinical description: subjective experience of being fatigued; cadence i.e. variation in the short term; chronicity; precipitating and aggravating factors; relieving factors; severity; associated features; and b) subjective experience: motor features; cognitive features; problems centred around motivation and energy expenditure; sleep and behavioural responses; other feature;</p> <p>3 Definition of the symptom: subjective experience: motor features (paresis, motor deficit, weakness, heaviness, feet dragging, unable to stand, paresis of bulbar muscles may affect speech with both dysarthria and hypophonia being possible); subjective experience: cognitive features (inability to sustain mental functioning, perception of increased mental effort, poor attention, nominal dysphasia, problems with memory and recall); subjective experience: motivation, energy and need to rest (sense of lack of motivation, to sustain or complete a task mental or physical, excessive sense of effort, activity avoidance, <i>'can't be bothered'</i>, sense of limited energy to do things); subjective experience: behavioural response including sleep (activity cessation and subsequent rest, devoid stimuli, sleep); subjective experience: other (excessive yawning most of the time, sweating);</p> <p>4. Cadence: fatigue could occur at anytime of the day, even on waking, some had a clear circadian rhythm to the development of fatigue e.g. less fatigued in the morning and more fatigued in the afternoon 2-3 pm);</p> <p>5. Chronicity: (fatigue caused disability on a timescale measured in the order of years, in some fatigue become worse as the duration of MS increased, in others fatigue was no longer a prominent symptom)</p> <p>6. Precipitating/ aggravating factors: physical and mental activity, long periods of inactivity or immobility, MS relapse, pain, food ingestion, infections, poor quality disturbed sleep, heat, humidity, warm room, hot shower, psychological distress, anxiety, stress, depression, nocturnal sleep was often un-refreshing;</p>	<p>It could appear spontaneously or may be brought on by mental or physical activity, humidity, acute infection and food ingestion;</p> <p>It can be relieved by daytime sleep or rest without sleep, and could occur at any time but was usually worse in the afternoon;</p>

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
			<p>7. Relieving factors: opposite of the precipitating factors, same were the same reflecting apparent contradiction in the data, sleep in the day (5min-3hrs), rest, physical and mental inactivity, rhythmic aerobic, exercise – improved sense of well-being and improved exercise tolerance, pacing, metered energy expenditure, cooling,</p> <p>8. Severity: wide range of severity, mild cold be just slight reduction in dexterity, severe was all consuming with even the slightest activity requiring great effort and limitation by repeated or prolonged period of rest,</p> <p>9. Associated features: interrupted sleep, pain, nocturnal walking, increased spasticity,</p> <p>10. Homogeneity: no features related to time or point of disease, or specific disease type, age or sex,</p> <p>11. Summary definition: fatigue defined as reversible, motor and cognitive impairment with reduced motivation and desire to rest,</p>	
Repping-Wuts et al (2008) The Netherlands	<p>1. RA</p> <p>2. Qualitative (specific design not stated)</p> <p>3. None stated</p>	<p>3 themes,</p> <p>2 tables presenting quantitative data on disease related characteristics and QoL scores and sleep quality</p>	<p>The fatigue experience: Fatigue verbalised as everyday experience with a variety in duration and intensity, sudden and exhausting, causing frustration and anger;</p> <p>RA main cause of fatigue;</p> <p>1. Mostly unpredictable: variable, sudden, not occurring at regular times or same days of the week, with a variety in duration and intensity, physical, temporal, frustrating, causing anger, exhausting, aggravating and acceptable,</p> <p>-cause of fatigue: no reason, use of medication, age, co-morbidity, disability, RA, stiffness in the joints, decreased physical activity, unrest, wakening, stress, doing too much,</p> <p>2. Affecting everyday life: relationships, leisure time, emotional aspects, restricting work or changing work hours, unable to participate in leisure activities, asking for help with household activities, give up sport,</p>	<p>The consequences are overwhelming and influence patients' everyday tasks, attitudes and leisure time;</p> <p>Patients are left to find their own management strategies by trial and error and describe pacing and rest, relaxation and planning activities as the most appropriate interventions;</p> <p>Downward comparison and acceptance as part of the disease are also reported as successful coping strategies for fatigue;</p>

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
			irritability, crying, decreed motivation and concentration, poor sleep quality, 3. Professional care and self-management are variable: pacing, rest, relaxation (reading, listening music, TV), acceptance, not wanting to be a complainer, try to manage fatigue alone, most did not remember or did not receive professional advice, professional support was not patient-specific, and often not suitable to carry out some, need for more information was identified,	Most patients did not discuss fatigue with clinicians explicitly, accepting that they were told that fatigue is part of the disease and believing that they have to manage it alone;
Blaney & Lowe-Strong (2009) Northern Ireland	1. MS 2. Phenomenological approach (specific design not stated, but interpretive, no references) 3. None stated	3 themes, 13 sub-themes: 4, 9 in theme 1 and 2 respectively; no sub-themes in theme 3	1. Revealing communication changes: communication impairment, - fatigue increases the frequency and severity of cognitive communication symptoms (language processing deficits, motor speech symptoms); - new communication symptoms become apparent (language processing difficulties and dysarthria); - listeners become more aware of communication symptoms (difficult to express true meaning & feelings, being seen as drunk or lazy); - communication is a sensitive gauge of level of fatigue (slurred speech); 2. Concealing and coping: covert and overt strategies - working behind the scenes/covered strategies (problems word finding, memory difficulties - use of pre-prepared list, prompts and cues, organisation and pre-planning); - overt coping strategies; energy efficiency; reduce activity; schedule activity; humour; explain, acknowledge, educate; notes for communication and memory; the impact of fatigue on communication in MS; 3. Barriers to participation: reduced socialisation, embarrassment	Increase in the severity in communication symptoms and the onset of new communication symptoms when experiencing fatigue were reported; A range of covert and overt strategies employed to manage fatigue and communication changes; The complex interplay between symptoms of fatigue and communication, strategies employed to manage these symptoms and societal attitudes was reported in 'barriers to participation';
Nikolaus et al (2010)	1. RA 2. Qualitative (specific design not stated)	3 first level headings, and 3 second level headings	1. Interindividual differences: negative emotions related to fatigue (low mood, feeling useless, being oversensitive, irritable, unable to deal with things, being catty, angry, depressive mood, feeling miserable, rebellious, unpleasant, sad, down, despondent, frustrated, aggressive, anxious, self-	Inter-individual differences in the experience and impact of fatigue;

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
The Netherlands	3. None stated		<p>pitting, misunderstood); consequences of fatigue (reduced mobility and activity, unable to support others, fatigue related stress, unable to work, being tired during the day); coping with fatigue (accept, fight, plan ahead);</p> <p>2. Different forms of fatigue: mental, physical fatigue; with or with pain, with or without dizziness, with or without the desire to go to bed and sleep);</p> <p>3. Benefit finding: making conscious decisions in life (prioritising), learning to let things go, learning to appreciate the beneficial aspects of rest, fatigue can make daily life easier, being able to fall asleep easier, the boss can see when one is really tired and being able to use fatigue as an excuse,</p>	<p>Varying forms of fatigue were described;</p> <p>Different patterns in emotions, consequences and management of fatigue were found;</p> <p>Younger women with multiple daily roles seemed to be vulnerable to the negative impact of fatigue, existence of differences in fatigue experience according to gender, age, daily roles; ;</p> <p>Patients also reported positive aspects of fatigue;</p>
Tsai et al (2010) Taiwan	<p>1. Cancer</p> <p>2. Qualitative (specific design not stated)</p> <p>3. None stated</p>	3 themes	<p>1. Factors related to fatigue: cancer treatment and symptom distress (chemotherapy, nausea, vomiting, poor appetite, malnutrition, poor sleep); impact of emotions (emotions caused by becoming ill, unhappiness, discomfort, uneasiness, negative emotions);</p> <p>2. Interpretations of fatigue: an inevitable normal reaction; embarrassed to share with others; faced fatigue alone,</p> <p>3. Ways to deal with fatigue: practical-down-to earth changes (doing less work, increasing frequency of rest, reducing frequency of going out, procuring ready-made meals instead of cooking, doing exercise); psychological adjustments (optimistic positive open-minded attitude); support systems (health professionals, families, friends, individual's religious power, will power,</p>	<p>Factors related to fatigue arose from treatment, symptom distress and the impact of their emotions;</p> <p>Fatigue was interpreted as an inevitable normal reaction, and participants were embarrassed to share its occurrence with others;</p> <p>Although fatigue made participants suffer, they found the ways to decrease the feeling of fatigue using psychological adjustments,</p>

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
				practical changes and support systems;
Pongthavor nkamol et al 2012 Thailand	1. Cancer 2. Ethnoscience 3. None stated	2 segregates, 4 sub-segregates, and several elements of fatigue	Two segregates and numerous sub-segregates were identified: 1. Essential/constant: feeble and easily tired (too tired to breath, too tired to do things, burned out /no energy, too tired to respond to others, want to lie down); altered cognition (forgetful, absent-minded, can't think, unable to the words/voiceless) 2. Intermittent: loss of mental strength (angry, more emotional, bored, discouraged, feel lifeless, withdrawn, worried, anxious); difficulty sleeping (half asleep and half awake, dazed, dog sleep)	The primary meanings of fatigue in the Thai data were related to temporality, whereas the primary meanings of fatigue in the Canadian data were related to the location of the fatigue (mind/body); The findings help to understand the social construction of fatigue;
Siegel et al (2012) USA	1. Cancer 2. Qualitative (specific design not stated) 3. None stated	4 groups of causal attributions for fatigue	1. Cancer treatment as the master attribution, chemotherapy, radiation, surgery, 2. Multiple attributions and explanatory ambiguity: older age, cancer, depression, anaemia, co-morbidities, antidepressant medication, 3. Age and other less-threatening causes of fatigue: treatment after-effects, sleep disturbance, loneliness) 4. Cancer, but not cancer progression as one of many causes	Patients who identified cancer-related treatment as the master attribution for fatigue seemed less distressed about the symptom; Multiple causes of fatigue e.g. combination of cancer, treatment and nonthreatening causes were also offered; Patients seemed to resist identifying disease severity as a cause and appeared motivated to normalise and minimise the symptom, decreasing its threatening impact;

Study	1. Condition 2. Methodology 3. Theoretical orientation	Way of data presentation	Study themes and results	Main findings
Spichiger et al (2012) Switzerland	1. Cancer 2. Grounded theory 3. None stated	7 themes	<p>1. Being informed about fatigue – most were adequately informed about fatigue by health professionals, brochure on fatigue,</p> <p>2. Experiencing fatigue – all reported fatigue during chemotherapy, but intensity, signs, and pattern varied, inability to remain active, lack of energy, heaviness of the body, feeling as unable to mobilise, having to sleep, problems concentrating, worse fatigue during the evening,</p> <p>3. Enduring fatigue – accepting fatigue, bothersome, irritating, limiting, unbearable, willing to endure it as the price of successful treatment,</p> <p>4. Experiencing fatigue in relation to life and illness circumstances – illness, living and working situations, their available support influenced their dealing with fatigue, modified their family life, activities, unable to carry on with daily activities,</p> <p>5. Experiencing or lacking support – support from family, friends, neighbours,</p> <p>6. Fatigue-related self-care – intuitive reaction guided by their body, rest, breaks, sleeping, napping, walking, gardening, hobbies, relaxation, exercise, sleeping pills, sexual activity were invigorating, alternative medicine,</p> <p>7. Handling fatigue in the absence of advice from health professionals – health professionals advice was markedly absent, no counselling by health professional was reported, many did not expect advice regarding fatigue,</p>	<p>At the start of chemotherapy, health professionals informed patients that common side effects include fatigue;</p> <p>While all participants experienced different dimensions of fatigue, all were willing to endure it for the sake of an expected improvement in their conditions;</p> <p>Individuals' fatigue experiences depended largely on their particular life and illness circumstances;</p> <p>Most engaged in fatigue-related self-care activities and managed the symptom on their own;</p> <p>Communication with or input from health professionals was virtually absent during chemotherapy;</p>

Appendix VII Themes created from findings of fatigue in chronic conditions

References (chronologically)																							
Themes	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19	20	21	22	23
1. Description and nature of fatigue		•		•	•	•	•		•	•	•	•	•	•	•	•	•		•				
2. Components and trajectory of fatigue	•	•	•							•	•	•					•		•		•		•
3. Antecedents and aggravating factors of fatigue		•		•					•	•	•		•			•	•			•		•	•
4. Pervasive impact and consequences of fatigue on life	•	•	•	•	•	•	•	•	•	•	•	•	•	•		•	•	•	•				•
5. Helpful and unhelpful strategies coping and managing fatigue		•		•	•	•	•	•	•		•				•	•	•	•	•	•			•

Key: • - theme present in the paper; 01 - Glaus et al 1996; 02 – Pearce et al 1996; 03 – Ream & Richardson 1997; 04 – Stuifbergen & Rogers 1997; 05 – Magnusson et al 1999; 06 – Flensner et al 2003; 07 – Lindqvist et al 2004; 08 – Porock & Juenger 2004; 09 – Potter 2004; 10 – Gledhill 2005; 11 – Hewlett et al 2005; 12 – Olsson et al 2005; 13 – Bennett et al 2007; 14 – Olson et al 2007; 15 – Wu & McSweeney 2007; 16 – Mills & Young 2008; 17 – Repping-Wuts et al 2008; 18 – Blaney & Lowe-Strong 2009; 19 – Nikolaus et al 2010; 20 – Tsai et al 2010; 21 – Pongthavornkamol et al 2012; 22 – Siegel et al 2012; 23 – Spichiger et al 2012

Appendix VIII Quality appraisal results of the reviewed studies on fatigue in chronic conditions

(Adapted from Paterson et al 2001, and CASP guidelines - www.casp-uk.net) References (chronologically)

Assessment Criterion	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19	20	21	22	23
Research design																							
Purpose of the research clearly stated?	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Research question explicitly expressed?	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Identification of assumptions and preconceptions	x	x	•	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Identification of theoretical framework	•	•	•	x	•	•	•	x	•	•	x	•	x	•	•	x	x	•	x	x	•	x	•
Methodology fit with the purpose of the study?	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Role of researcher and consideration of bias?	•	•	•	x	•	•	x	x	•	x	•	•	x	x	x	•	•	•	•	x	x	x	x
Sampling strategy																							
Description of the sampling procedure	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Description of the participants?	•	x	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Identification of inclusion criteria?	•	•	•	•	•	x	•	x	•	x	•	•	•	•	•	•	•	•	•	•	•	•	•

Assessment Criterion	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19	20	21	22	23
Data gathering																							
Description of data gathering procedures?	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Does data collection fit with methodology?	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Are any tools (interview/focus group guidelines) provided?	•	•	•	x	•	•	•	x	•	•	•	x	•	•	•	•	•	•	•	•	•	x	x
Description of gaining access?	•	•	•	•	•	•	•	•	•	•	x	•	•	•	•	•	•	•	•	•	•	•	•
Discussion of time frame of data gathering?	•	x	x	x	•	x	•	x	x	x	x	•	x	x	•	x	•	x	x	•	x	•	x
Data analysis																							
Description of the method(s) used?	•	•	•	x	x	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Does data analysis method fit with methodology?	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Identification of relationship between categories or themes?	•	x	•	•	•	•	•	•	•	•	•	•	•	•	•	x	•	•	•	•	•	x	•
Is the analysis well supported by representative quotes/findings?	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Findings																							
Are findings presented in a way consistent with methodology?	x	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Are findings a likely product of the study?	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•

Assessment Criterion	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19	20	21	22	23
Conclusion, discussion and implications for further research																							
Discussion pertains to all significant findings?	•	x	•	•	•	•	•	•	•	•	•	•	•	•	x	•	•	•	•	•	•	•	•
Identification of study limitations?	x	x	x	x	•	x	x	x	x	x	•	x	•	x	•	•	•	x	x	•	•	•	•
Do the interpretive statements correspond with findings?	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Examination of the findings with existing literature?	•	x	•	x	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Clear indication of directions for future research?	•	•	•	•	•	•	•	x	•	x	x	•	•	•	x	•	•	x	•	•	•	•	•
Evidence of rigour																							
Credibility, Transferability, Dependability, Confirmability	•	x	•	x	•	•	x	x	•	x	x	•	x	x	x	•	•	•	x	•	•	x	x
Ethical considerations																							
Are ethical assurances and evidence of participant consent, given?	•	•	•	x	•	•	•	•	•	•	•	•	•	•	•	•	•	•	x	•	•	•	•

Key: Consensus definition •=YES, x=NO; • - theme present in the paper; 01 - Glaus et al 1996; 02 – Pearce et al 1996; 03 – Ream & Richardson 1997; 04 – Stuifbergen & Rogers 1997; 05 – Magnusson et al 1999; 06 – Flensner et al 2003; 07 – Lindqvist et al 2004; 08 – Porock & Juenger 2004; 09 – Potter 2004; 10 – Gledhill 2005; 11 – Hewlett et al 2005; 12 – Olsson et al 2005; 13 – Bennett et al 2007; 14 – Olson et al 2007; 15 – Wu & McSweeney 2007; 16 – Mills & Young 2008; 17 – Repping-Wuts et al 2008; 18 – Blaney & Lowe-Strong 2009; 19 – Nikolaus et al 2010; 20 – Tsai et al 2010; 21 – Pongthavornkamol et al 2012; 22 – Siegel et al 2012; 23 – Spichiger et al 2012;

Appendix IX Recommendations from the reviewed qualitative studies on fatigue in chronic conditions

Study	Recommendations for further research
Glaus et al (1996) Switzerland and UK	<ul style="list-style-type: none"> - Develop instrument to assess the physical, affective and cognitive components of fatigue - Test new methods to assess and treat fatigue - Larger studies are needed to validate the experience of fatigue - To distinguish between different types of fatigue so different management methods could be developed - Develop measures that could interrupt the cycle between fatigue and increased need for rest and sleep, inactivity, sadness or cognitive problems
Pearce & Richardson (1996) UK	-A larger sample and longitudinal research designs incorporating several interviews with each informant would provide further understanding and clarification of the phenomenon of fatigue
Ream & Richardson (1997), UK	-Further systematic qualitative enquiry is necessary to determine the experiences of patients with a cross-section of other illnesses and to assess the saliency of these findings for other clinical populations
Stuifbergen & Rogers (1997) USA	-Further research is needed to explore the effects of specific interventions and combinations of interventions in the management of fatigue
Magnusson et al (1999) Sweden	<ul style="list-style-type: none"> -To better specify the dimensions and their signs and symptoms to find out how the different dimensions affect a patient -To understand how fatigue affects person over time a longitudinal study is required
Flensner et al (2003) Sweden	-Relationship between constructive and non-constructive perceptions of fatigue need to be investigated and their conditioning impact on factors affecting self-care
Lindqvist et al (2004) Sweden	<ul style="list-style-type: none"> -Current study should be replicated with a larger sample in different cultures exploring a struggle between body and mind -To test approaches to fatigue management incorporating a combination of medical treatment, physiotherapy, occupational therapy -Nursing and patients' perspective regarding the meanings of fatigue and strategies to help patients to live with the disabling experience of fatigue

Study	Recommendations for further research
Porock & Juenger (2004) USA	None stated
Potter (2004) UK	-There is a need for innovative interventions to help patients to cope with fatigue
Gledhill (2005) France	None stated
Hewlett et al (2005) UK	None stated
Olsson et al (2005) Sweden	-To investigate what kind of interventions help women with MS to manage their everyday lives and to maintain a sense of normality despite fatigue and illness -There is also a need for empirical research to evaluate different kind of interventions
Bennett et al (2007) Australia	-Further investigations of fatigue states in cancer and other settings to explore phenotypic similarities
Olson et al (2007) Canada	-Deeper understanding of the social and cultural constructions of fatigue experience is required -Cross-cultural ethnographic studies could assist in the explication of patterns in beliefs and values regarding fatigue, and aid the development of interventions that were clinically effective and sensitive to social and cultural norms
Wu & McSweeney (2007) USA	None stated
Mills & Young (2008) UK	-To explore a combination of different explanations of the individual features of fatigue to help to understand the physiology of the symptom as a whole
Repping-Wuts et al (2008) The Netherlands	-Further research is needed to explore the communication between RA patients and healthcare professionals to discuss fatigue explicitly
Blaney & Lowe-Strong (2009) Northern Ireland	None stated

Study	Recommendations for further research
Nikolaus et al (2010) The Netherlands	-A theoretical, comprehensive model of fatigue and its experience is still lacking, the dimensions of RA fatigue and possibly related patients characteristics should be examined in more detail -Differences between patients and the differences in the experience and descriptions of fatigue should be explored via quantitative research
Tsai et al (2010) Taiwan	-Research in other locations is required to ascertain if geographical factors influence the experience of CRF for women with breast cancer
Pongthavornkamol et al 2012 Thailand	-Further research is needed to determine whether different cultures, beliefs and values would impact on individuals' perception of fatigue
Siegel et al (2012) USA	-Further research is required into a complex relationship between symptom interpretation and psychological well-being and to refine our understanding of how fatigue and other cancer-related symptoms lead to distress
Spichiger et al (2012) Switzerland	-Additional research is necessary to integrate evidence-based interventions against chemotherapy-related fatigue effectively into standard practice

Appendix X Theory extracted from qualitative studies on fatigue in chronic conditions

Study / Condition	Methodological & Theoretical orientation	Ways of data presentation	Study themes and sub-themes
Glaus et al (1996) Switzerland & UK; Cancer	Grounded theory; Theory generation	3 main categories with 16 themes (occurrence, frequency and distribution themes presented in numbers and percentages, pie chart and figure)	1. Physical sensation of tiredness (59% of all themes): decreased physical performance; weakness/no strength; unusual need for sleep; unusually tired/feeling worn-out ; unusual need for rest; 2. Affective sensation of tiredness (29% of all themes): decreased motivation; need to force oneself to overcome inactivity; no energy; sadness; anxiety; no fighting spirit; 3. Cognitive sensation of tiredness (12% of all themes): lack of concentration; problems in thinking; mental tiredness; sleeping problems at night ;malaise;
Pearce & Richardson (1996) UK; Cancer	Phenomenology (not stated which, but interpretive); None stated	5 themes	1. The nature of fatigue 2. Causes of fatigue 3. Consequences of fatigue 4. Strategies for coping with fatigue 5. The trajectory of fatigue
Ream & Richardson (1997) UK; Cancer	Phenomenological approach (not stated which, but descriptive); None stated	5 themes (only textural themes presented, structural themes not presented in this paper)	1. The physical sensation embodied in fatigue 2. The mental sensations embodied in fatigue 3. The impact of fatigue on everyday functioning; 4. The emotional feelings evoked by fatigue 5. The impact of fatigue on perceived control 6. The impact of emotions on the management of fatigue;

Study / Condition	Methodological & Theoretical orientation	Ways of data presentation	Study themes and sub-themes
			<p>7. The importance of recognising and understanding fatigue;</p> <p>8. The significance of setting and reaching goals;</p> <p>9. The effectiveness of self-care in the alleviation of fatigue;</p> <p>Only the first five themes (textural) related to the experience of fatigue were presented, the final four themes (structural) concerned with individuals' capacity to manage their fatigue were not presented.</p>
Stuifbergen & Rogers (1997) USA; MS	Qualitative descriptive design (specific design not stated); None stated	4 broad areas (themes) with several subthemes	<p>1. The experience of fatigue: fatigue as an ever-present ongoing experience; pervasive impact of fatigue on life; exacerbation of symptoms with increasing fatigue; fatigue as paralysing force; the undertow effect of severe fatigue;</p> <p>2. Antecedent factors of fatigue: lifestyle patterns; environmental factors; perceived stress;</p> <p>3. Self-care strategies to manage fatigue: energy conservation; recharge efforts; enhancing resistance to fatigue; temperature control;</p> <p>4. Influences on selection and initiation of self-care strategies: suggestions from friends, family and others with MS; ideas gleaned from publications; self-discovery</p>
Magnusson et al (1999) Sweden, Cancer	Grounded theory; None stated	2 themes with 3 categories and 11 dimensions; Figure for the process of fatigue, tables	<p>Theme 1: the categories, dimensions and qualities of fatigue:</p> <p>1. Experience of fatigue: loss, need, malaise, psychological stress, emotional affection, abnormal weakness, difficulty in taking the initiative;</p> <p>2. Consequences of fatigue: social limitation, affected self-esteem, affected quality of life;</p> <p>3. Actions: coping</p> <p>Theme 2: the words used by participants to describe fatigue</p>

Study / Condition	Methodological & Theoretical orientation	Ways of data presentation	Study themes and sub-themes
Flensner et al (2003) Sweden; MS	Phenomenological approach (Husserl's philosophy); The empirical phenomenological psychological method (Karlsson 1995)	2 levels of analysis: 2 themes, 10 sub-themes	Level 1: A situational structure of MS-related fatigue – one description of the noetic side (description of one participant's experience of fatigue) Level 2: A general meaning structure of MS-related fatigue – the noematic side (with 2 themes and 6 & 4 sub-themes each respectively) 1. Themes of non-constructive perceptions of fatigue: time-consuming and all absorbing; involvement of the body; loss of energy; emotional perceptions; dependency; restrictions of life; 2. Themes of constructive perceptions: desire for acceptance of life; desire for a structured daily living; means of assistance becoming body-as-lived - typological structures
Lindqvist et al (2004) Sweden; Cancer	Phenomenological -hermeneutic approach; Ricoeur philosophy to understand the ways of being in the world	Two levels of analysis: naive understanding and structural analysis with 2 themes and 5 sub-themes; comprehensive understanding and reflections (discussion and comparison with broader literature)	Level 1: naive understanding Level 2: Structural analysis 1. Being unable to live the life you want to live: being trapped in a failing body; becoming dependent on and a burden to others; not having the strength to be with others; 2. Longing for a healthy life: struggling in vain against fatigue; hoping, but not expecting, to overcome fatigue Comprehensive understanding - discussion

Study / Condition	Methodological & Theoretical orientation	Ways of data presentation	Study themes and sub-themes
Porock & Juenger (2004), USA; Cancer	Qualitative (specific design not stated); None stated	4 themes	<ol style="list-style-type: none"> 1. Life-disrupting severity of fatigue 2. Altered sleep patterns 3. Informational needs met 4. Advice for other patients
Potter (2004) UK; Cancer	Phenomenology, Heidegger's hermeneutic circle; None stated	5 themes and several categories, Table and figure – The interconnectedness of the themes	<ol style="list-style-type: none"> 1. Physical consequences of fatigue: impact on daily activities/effects on quality of life, physical sensations/descriptions, tiredness/energy levels, other symptom burden, causes of fatigue; 2. Psychological consequences of fatigue: poor memory/concentration, stress and worry, uncertainty/unpredictability/loss of future, striving for normality, loss of independence, feelings of isolation and loneliness; 3. Social consequences of fatigue: family dynamics changed, effects on family/carer, loss of pleasurable activity; 4. Spiritual consequences of fatigue: hope/hopelessness, fatigue related to dying, difficulty in accepting situation/need for assistance; 5. Struggling to cope with fatigue: helpful/unhelpful coping mechanisms;
Gledhill (2005) France; Cancer	Grounded theory; Theory generation	7 themes, Percentages & mean, Model of interrelationship between symptoms (physical, psychological, social),	<ol style="list-style-type: none"> 1. Physical manifestation of fatigue (35% of all themes): lack of stamina; increased time spent resting and sleeping than before illness; decreased energy; weakness/lack of strength; slowing down in physical activities; decreased in sexual activities; 2. Affective manifestations of fatigue (41% of all themes): low spirits; lack of motivation; anxiety, anxious-depressive trait ; mood swings, irritability, anger, aggressiveness, impatience, frustration; need to force oneself to engage in activity; intrusive thoughts; lack of courage, will power; lack of vitality, vigour;

Study / Condition	Methodological & Theoretical orientation	Ways of data presentation	Study themes and sub-themes
		Model for evolution of fatigue	<p>3.Cognitive manifestations of fatigue (24% of all themes): difficulty in concentrating; difficulty in resolving problems, reasoning; lack of interest in people, activities, information, environment; somnolence during the day; problems in memorisation, recall; lack of creativity; lack of lucidity;</p> <p>4.Major themes of distress revealed through the different metaphors, images and expressions used by participants: helplessness; threatening experience; worn out; isolation; culpability; loss of identity; loss of life's meaning; dependence</p> <p>5. The fatigue cycle in cancer patients</p> <p>6. Distress caused by cancer-related fatigue</p> <p>7.Symptoms implicated by patients in the development of CRF</p>
Hewlett et al (2005) UK; RA	Qualitative (specific design not stated); None stated	3 themes, Figure of the relationship between themes, categories and concepts	<p>1.Overwhelming and different from normal tiredness ('wipeout'): - components - physical, cognitive, emotional; not normal - not earned, unresolving; triggers - everyday tasks, doing too much; attributed causes - RA/pain, working harder, tasks take longer, sleep;</p> <p>2.Cosequences permeate every sphere of life: activities – work, household, leisure; life on hold – can't plan; role – family, social; relationships – strained; emotions – frustration, irritable, self-esteem, resentment;</p> <p>3.Self-management is variable and professional support is rare: self-management : attitude, pace, rest, variable success; professional care: not discussed, dismissed, variable success</p>
Olsson et al (2005) Sweden; MS	Phenomenological hermeneutic	2 levels of analysis: level 1 - naive understanding with 2 themes and 5 subthemes;	<p>Level 1: naive understanding</p> <p>1.Experiencing the body as a barrier: a feeling of having a heavy body; a feeling of having the will but not the ability; a feeling of saving strength an needing to rest;</p>

Study / Condition	Methodological & Theoretical orientation	Ways of data presentation	Study themes and sub-themes
	(Ricoeur, 1976); None stated	Level 2 – comprehensive understanding and reflections on findings (discussion and comparison with broader literature)	2.Experiencing a different absence: an unusual and invisible feeling; a feeling of being absent Lvel 2: comprehensive understanding and reflections on the findings
Bennett et al (2007) Australia; Cancer	Qualitative (specific design not stated); None stated	4 categories of symptoms, 3 categories of behavioural impact, Language describing fatigue, Model: characteristics of fatigue	First level analysis sorted into four categories: 1.Fatigue: 'abnormal tiredness' 2.Neurological impairment (memory) 3.Mood disturbance (sadness, frustration) 4.Miscellaneous symptoms: symptoms associated with other conditions such as menopause, migraine headaches; Second categorisation – three categories of impact of fatigue: 1.Physical consequences: inability to function at work and at home 2.Psychological consequences : emotional, behavioural 3.Social consequences: workplace, home Language describing fatigue, Model of characteristics of fatigue
Olson et al (2007) Canada; cancer	Ethoscience method; Adaptation model, Stress theory	3 domains, 2 segregates, and 5 sub-segregates, Figures: Fatigue adaptation model, and Moving between tiredness, fatigue, and exhaustion	1.Three domains: tiredness, fatigue, exhaustion; 2.Two segregates for each domain: mind, and body; 3.Sub-segregates for each segregates: Mind – emotion, and thinking; Body – muscles, how the body feels, and interactions with others

Study / Condition	Methodological & Theoretical orientation	Ways of data presentation	Study themes and sub-themes
Wu & McSweeney (2007) USA; Cancer	Phenomenological approach as developed by Husserl and Heidegger; Embodiment and self-body relation	6 themes, and several subthemes	1.Different fatigue 2.Physical sensations: the object body, 3. I cannot.. (fighter, surrender) 4.Emotional sensations: re-unification: harmony of lived body and object body: reasoning; support; the talk between self and body; 5. Gaining the sense of control; reflection/meaning; 6.Fatigue as holistic experience
Mills & Young (2008) UK; MS	Mixed-methods study with qualitative phase; None stated	4 main headings with several categories and related descriptions, prevalence for each theme presented in %; 5 grouped themes with prevalence presented in % for each theme; tables and % for different features of fatigue	1.Somantics of fatigue: use of words 2.Symptom framework: a) clinical description: subjective experience of being fatigued; cadence i.e. variation in the short term; chronicity; precipitating and aggravating factors; relieving factors; severity; associated features; b) subjective experience: motor features; cognitive features; problems centred around motivation and energy expenditure; sleep and behavioural responses; other feature; 3 Definition of the symptom 4 Summary definition
Repping-Wuts et al (2008) The Netherlands; RA	Qualitative (specific design not stated); None stated	3 themes, 2 tables presenting quantitative data on disease related characteristics and QoL scores and sleep quality	The fatigue experience: 1. Mostly unpredictable 2. Affecting everyday life 3. Professional care and self-management are variable

Study / Condition	Methodological & Theoretical orientation	Ways of data presentation	Study themes and sub-themes
Blaney & Lowe-Strong (2009) Northern Ireland; MS	Phenomenological approach (specific design not stated, but interpretive, no references); None stated	3 themes, 13 sub-themes: 4 and 9 in theme 1 and 2 respectively; no sub-themes in theme 3	<ol style="list-style-type: none"> 1. Revealing communication changes: communication impairment 2. Concealing and coping: covert and overt strategies 3. Barriers to participation: reduced socialisation, embarrassment
Nikolaus et al (2010) The Netherlands; RA	Qualitative (specific design not stated); None stated	3 themes and 3 sub-themes	<ol style="list-style-type: none"> 1. Interindividual differences: negative emotions related to fatigue; consequences of fatigue; coping with fatigue; 2. Different forms of fatigue: mental, physical fatigue; 3. Benefit finding
Tsai et al (2010) Taiwan; Cancer	Qualitative (specific design not stated); None stated	3 themes	<ol style="list-style-type: none"> 1. Factors related to fatigue: cancer treatment and symptom distress; impact of emotions; 2. Interpretations of fatigue: an inevitable normal reaction; embarrassed to share with others; 3. Ways to deal with fatigue: practical-down-to earth changes; psychological adjustments; support systems
Pongthavornkamol et al 2012 Thailand; Cancer	Ethnoscience; None stated	2 segregates, 4 sub-segregates, and several elements of fatigue	<p>Two segregates and numerous sub-segregates were identified:</p> <ol style="list-style-type: none"> 1. Essential/constant characteristics of fatigue: feeble and easily tired, and altered cognition 2. Intermittent characteristics of fatigue: loss of mental strength, difficulty sleeping

Study / Condition	Methodological & Theoretical orientation	Ways of data presentation	Study themes and sub-themes
Siegel et al (2012) USA; Cancer	Qualitative (specific design not stated); None stated	4 groups of causal attributions for fatigue	<ol style="list-style-type: none"> 1. Cancer treatment as the master attribution 2. Multiple attributions and explanatory ambiguity 3. Age and other less-threatening causes of fatigue 4. Cancer, but not cancer progression as one of many causes
Spichiger et al (2012) Switzerland; Cancer	Grounded theory; None stated	7 themes	<ol style="list-style-type: none"> 1. Being informed about fatigue 2. Experiencing fatigue 3. Enduring fatigue 4. Experiencing fatigue in relation to life and illness circumstances 5. Experiencing or lacking support 6. Fatigue-related self-care 7. Handling fatigue in the absence of advice from health professionals

Appendix XI Table of reviewed papers utilising descriptive phenomenological design

Study	Study aims	Data collection method and sample size	Data analysis	Themes identified	Rational for selecting descriptive phenomenology	Methodological challenges and solutions
Appelin & Bertero, 2004, Sweden	To obtain an understanding of patients' experience of palliative care at home	One face-to-face interview (45-60 min), with use of interview guide; 6 patients	Giorgi method (7 step process) (1985)	1) Safe but unsafe at home; 2) A sense of powerlessness; 3) Change of everyday life; 4) Hope and belief in the future	No interpretation, but description of experience; seeks the essence of the phenomenon through the method of free imaginative variations; giving voice to the patients	None identified
Ek & Ternstedt, 2008, Sweden	To describe the essential structure of the lived experience of living with severe COPD during the palliative phase of the disease	One face-to-face interview (20-90 min), using 5 open ended questions; 8 patients	Giorgi method (5 step process) (1985)	1) Lacking physical strength 2) Being forced to forgo activities and material things 3) Being socially and existentially alone 4) Experiencing meaninglessness 5) Experiencing meaningfulness and belongingness	The guiding principle was 'to go to the things themselves' - to be open to the everyday world where people are living; searching for the variations of experiences and for what the experiences have in common, the structure of essence	Bracketing the researcher's pre-understanding of the phenomenon is important to be open to the patient's lived experience. No solution provided
Flensner et al 2003, Sweden	To describe MS-related fatigue as lived by a group of individuals diagnosed with MS	In-depth unstructured interview (1-1.5 hrs) with 2 questions; 9 individuals	An empirical phenomenological psychological method (5 step process), (Karlsson 1995)	1) Themes of non-constructive perceptions: time consuming and all-absorbing, involvements of the body, loss of energy, emotional perceptions, dependency, restrictions of life 2) Themes of constructive perceptions: desire for acceptance of life, desire for a structured daily living, means of assistance body-as-lived	To describe experiences of a phenomenon as the individual lives it, so called life-world experiences; to search for a general, but not universal, essence or meaning structure of the studied phenomenon	To enter the world of the respondents without expectations and with an as open and sensitive mind as possible. Solutions: constant return to the raw data by two researchers, a third researcher was checking all the texts during different analytical stages

Study	Study aims	Data collection method and sample size	Data analysis	Themes identified	Rational for selecting descriptive phenomenology	Methodological challenges and solutions
Gibson et al (2005), UK	To generate a detailed description of how adolescents with cancer manage their daily lives and how fatigue affects them	Semi-structured interviews (1-2 hours) using 11 open-ended questions; 8 adolescents	Moustakas' (1994) modification of the Stevick-Colaizzi method	1) Fatigue as phenomenon 2) Psychological effects; 3) Trying to regain normality 4) How is life affected? 5) What has changed? 6) Altered life perspectives	To describe phenomena as they manifest to the consciousness, to go back to the experience itself, the essence of the experience before it has been filtered through a person's perceptions of it; capturing life as it is lived	To avoid all presuppositions placed on experiences in advance, whether socio-cultural or scientific Solution: following the process of epoche and returning to the identified preconceptions as each transcript was analysed
Hellstrom et al (1999), Sweden	To describe the way in which the fibromyalgia patients understand the meaning of their illness	One face-to-face interview (30-50 min), using one opening question; 18 patients were interviewed, but only 10 taped interviews were transcribed and analysed	An empirical phenomenological psychological method (5 step process) (Karlsson 1995)	1) Onset 2) Unpredictable, invisible and incapacitating symptoms 3) Search for confirmation as an ill person 4) Search for a cause of the suffering 5) Demands placed upon oneself 6) Managing experience of threatening failure 7) Avoiding thoughts of future	Fibromyalgia could be understood as a conceptual solution that symbiotically serves both the patients' efforts to manage a sense of threatening incoherence and the doctors' desire to come to terms with what otherwise would challenge their biomedical action-repertoire	The interviewer took steps to comply with the principles of a phenomenological attitude and genuine dialogue; the 18 tapes were listened to three times and 10 of the most nuanced, original, interpretable and exhaustive ones were transcribed and analysed
Herlin & Wann-Hansson (2010), Sweden	To describe how haemodialysis patients (30-45 years of age), experience their dependence on HD treatment	In-depth interview (45-90 min), using one opening question; 9 patients	Giorgi's four basic principles (1985)	1) Sense of fear 2) Dependence on caregivers 3) Time lost in dialysis 4) Feeling of loneliness 5) Being on a waiting list for a kidney transplantation	To achieve experience-based knowledge of the phenomenon, to go back to the things themselves, to study everyday world as it appears for meanings to be understood	To handle researcher's pre-understanding, to minimise the influence no interviews took place at wards where researcher had previously worked, patients were selected by head nurses of the wards, and second author read the transcripts to verify the analysis

Study	Study aims	Data collection method and sample size	Data analysis	Themes identified	Rational for selecting descriptive phenomenology	Methodological challenges and solutions
Jonsson et al (2011), Sweden	To describe how patients experience the early postoperative period after colorectal cancer surgery	Interview (20-65 min) using one open-ended question; 13 adult participants	Giorgi method (1985)	1) Essence of the phenomenon 2) Experience of symptoms and difficulties: the uncontrollable body, pain and pain relief 3) Emotional experience: diagnoses and further treatment, thoughts about having an ostomy, lack of control and fear 4) Influences of the caring environment: the health care staff, the ward and technical equipment, fellow patient 5) Experience of being taken care of: nursing care, information, safety and trust 6) Factors influencing postoperative recovery	Phenomenology was found to be an appropriate method to describe the lived experience of a phenomenon	Phenomenological reduction and the search for the essence are important to avoid error and to achieve proper evidence. Solution: the authors strived to bracket all past beliefs, knowledge and opinions about the phenomenon; Avoidance of interpretation, construction and explanation by the authors consistently returning to the raw data, re-reading the data until they became familiar as a whole, involvement of multiple researchers in data analysis
Liu et al (2010), China	To explore the clinical preceptors' experience and the meaning of their lives in clinical teaching	Interviews (40-60 min); 20 clinical preceptors	Content analysis	1) Teaching is learning 2) Being unable to do what one would like to do 3) Experiencing bittersweet moments 4) Being a role model and acting as a mother	The approach is useful in investigating subjective phenomenon in the belief that essential truths about reality are grounded in lived experience	Use of bracketing - the researchers must bracket out of consciousness what they know or believe about the topic under investigation. Solution: limited literature review before data collection, involvement of multiple researchers in data analysis, data collection and analysis performed simultaneously to determine data saturation

Study	Study aims	Data collection method and sample size	Data analysis	Themes identified	Rational for selecting descriptive phenomenology	Methodological challenges and solutions
Pearce & Richardson (1996), UK	To describe the experience of fatigue from the perspective of cancer patients who had recently completed a course of chemotherapy	Interview (no duration specified), using 16 probing questions; 4 patients	Giorgi method (1985)	1) The nature of fatigue 2) Causes of fatigue; 3) Consequences of fatigue 4) Strategies for coping with fatigue 5) The trajectory of fatigue	Phenomenology attempts to study the human experience as it is lived and provides a perfect fit conceptually with the functions of clinical nursing and many of the research questions which evolve from clinical practice	Data collection and analysis occurred concurrently. Data from the interview, field notes and the self-reflective diary were read and re-read to achieve a sense of the whole
Ream & Richardson (1997), UK	To capture detail description of the fatigue experienced by individuals with cancer and chronic obstructive airways disease	Semi-structured interview (25-45 min), with use of prompts / guiding probes posed in an open-ended manner; 15 patients	Moustakas method (1994)	1) The physical sensations embodied in fatigue 2) The mental sensations embodied in fatigue 3) The impact of fatigue on everyday functioning 4) The emotional feelings evoked by fatigue 5) The impact of fatigue on perceived control 6) Composite textural description of fatigue	A phenomenological approach was used to elicit record and describe patients' perceptions of fatigue. It was chosen because it is particularly useful in describing subjective insights into the phenomenon	The researcher's preconceptions of fatigue were documented prior to the study (5 pre-conceptions stated), field notes were kept to help understanding of the transcripts and supplemented the researcher's memory, the transcripts were read and re-read, with the researcher's views bracketed, to provide the freedom to discover the interviewees' experiences
Ream et al (2006), UK	To investigate fatigue and its impact on quality of life in groups of adolescents during and after cancer treatment	Semi-structured interviews; 22 adolescents	Moustakas' method (Moustakas 1994)	1) Perceived well-being 2) Fatigue and associated frustration and distress 3) Perception of functioning	A mixed-methods study, phenomenology was used for the qualitative element. A rationale for the design selected relates to the mixed-methods design, rather than phenomenology alone	None identified in relation to the phenomenological part of the study

Appendix XII IBD-fatigue study advertisement

Copy of the advert to be published in NACC Newsletter for study Phase 1 and Phase 3a-c.

Dear NACC Member,

We are looking to recruit volunteers for a study of 'The prevalence and nature of fatigue (tiredness) in Inflammatory Bowel Disease (IBD)'. It aims to understand the experience of fatigue in IBD, how best to measure it, and the coping strategies people use to help them cope with it.

The study has ethics approval from the King's College London (KCL), study reference number: PNM/09/10-93, Psychiatry, Nursing and Midwifery Ethics Sub-Committee. We are looking to include people in the research who are over 18 years, have been diagnosed with IBD, can communicate in English and suffer from tiredness.

Participants will help the research through taking part in interviews and/or completing questionnaires about fatigue. If you would like to hear more about our research, or are interested in being involved with it, please contact Wladzia Czuber-Dochan at Wladzia.czuber-dochan@kcl.ac.uk or on 020 7848 3531.

Thank you for taking the time to read this letter.

Kind regards,

Wladzia Czuber-Dochan

PhD Student

King's College London

Florence Nightingale School of Nursing and Midwifery

James Clerk Maxwell Building

57 Waterloo Road

London SE1 8WA

Appendix XIII Participants selection grid

Gender											
Male (10)*						Female (10)					
IBD Type: Crohn’s disease or ulcerative colitis											
Crohn’s (5)			Colitis (5)			Crohn’s (5)			Colitis (5)		
Fatigue severity: Self-assessed by Visual Analogue Scale (VAS) on 0-10, with 0=no fatigue, and 10=most severe fatigue. Categories: Mild fatigue (1-3), Moderate fatigue (4-7), and Severe fatigue (8-10)											
Mild(2)	Moderate(2)	Severe(2)	Mild(2)	Moderate(2)	Severe(2)	Mild(2)	Moderate(2)	Severe(2)	Mild(2)	Moderate(2)	Severe(2)
Length of time since IBD diagnosis: newly diagnosed < 1 year, established disease >1 year											
<1 year (3)		>1 year (3)		< 1 year (3)		>1 year (3)		< 1 year (3)		>1 year (3)	

Key: * Numbers in brackets indicate an estimated number of participants in each category, with up to a maximum of 20 participants in total.

Appendix XIV Patient Information Sheet

INFORMATION SHEET FOR PARTICIPANTS (Phase 1& Phase 3 a-c)

REC Reference Number: PNM/09/10-93

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Study title: Prevalence and nature of fatigue in inflammatory bowel disease.



You are being approached as a member of NACC to participate in a study funded by the Big Lottery for NACC. We would like to invite you to participate in this postgraduate student's (Wladzia Czuber-Dochan) research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask Wladzia if there is anything that is not clear or if you would like more information. Her contact details are at the bottom of this information sheet.

Study aims and benefits

This study aims to explore the views of people with IBD about the nature and extent of fatigue and what coping strategies people use to manage the effects of fatigue in inflammatory bowel disease (IBD). Results from the study will be used to develop a questionnaire specific to assess IBD-fatigue. We are inviting people to talk about their experience of fatigue and to what extent it affects their daily life. We are also interested in knowing how they try and manage their fatigue. Hopefully you will find the interview interesting and that you will gain a sense of satisfaction in helping to develop a better quality of care for future patients.

Who can take part?

We are looking to include people in the research who are 18 years, have been diagnosed with IBD, can communicate in English and suffer from tiredness.

What participation involves?

We are looking for volunteers to take part in one of the four phases of the study. You will be asked if you have a preference in which part of the study you would like to participate. The phases of the study are:

1. Phase 1 (**duration 16 weeks**): This aims to explore the fatigue experienced by people with IBD and the coping strategies they use. If you decide to take part in this phase of the project, you will be interviewed. The interview will last 45-60 minutes. It will involve you talking about the effect fatigue has had on your life and the methods you have used to ease it. You will also be asked what help or advice you have had about coping with it. If you agree to take part Wladzia will contact you. She will arrange an interview at a time and place that is convenient for you. If you prefer, you can be interviewed by telephone. Interviews will be recorded and the information you provide will be used to form a questionnaire.
2. Phase 3a (**duration 4 weeks**): This phase aims to develop specific IBD-fatigue questions for the questionnaire. If you decide to take part in this phase of the

project, you will be asked to complete a questionnaire and be interviewed by the researcher. You will be asked how well the questions capture your feelings of fatigue. You will also be asked how easy questions are to understand.

3. Phase 3b (**duration 6 weeks**): This phase aims to hone the draft questionnaire for IBD-fatigue. If you decide to take part in this phase of the project, you will be posted a questionnaire. You will need to complete and return it within 2 weeks. You will be asked to comment on each question and say if you would keep, change or replace each one. You will also be asked about a layout of the questionnaire.
4. Phase 3c (**duration 16 weeks**): This phase aims to test the newly developed IBD-fatigue questionnaire. If you decide to take part in this phase of the project, you will be posted the same questionnaire to complete twice during a 2 month period. This will test if the questionnaire picks up changes in the severity of your fatigue. We will also ask you to complete one or two other questionnaires frequently used in other chronic conditions. **The questionnaires will ask you about your overall fatigue, its physical and mental aspects and how its impacts on your level of activity.** This will enable comparison of responses across questionnaires.

In phases 3a-c you will be asked questions about the nature, type and severity (on a scale 0-10) of your fatigue. You will also be asked for some personal details, e.g. age, gender, length of time you have been living with IBD. Stamped addressed envelopes will be provided for your reply. **If there is no response from you after 3 weeks of the initial correspondence a reminder letter will be sent.**

If you feel tired or decide that you no longer wish to continue you can withdraw from the study at any time, without having to explain why. If you during the interview feel that you have not expressed some ideas clearly enough and wish to discuss them further you can contact the researcher to arrange another appointment.

Are there any risks involved?

We will be discussing your illness experience and your methods of coping with it. Whilst we do not anticipate that this will make you upset, it is possible that some of the discussion might raise strong feeling/emotions. If you find this upsetting you can stop the interview and rearrange for another time or you can withdraw from the study at any time up to the point of data analysis. Also, if at the end of interview you feel you need help to discuss your feelings, the researcher can inform your GP, after obtaining your permission or help can be accessed through the Helpline of NACC.

Benefits to participants

If you would like, we can post you a summary/ publication of the study report once the study has finished. The researcher will keep a record of your interest in receiving a copy of the summary/publication.

Confidentiality

The interview will be audio-recorded to assist the researcher to adequately register your views. However you are free to ask for the recording to be stopped at any time. The interview will be kept confidential. Only the researcher and her supervisors will have access to read and listen to what is spoken about, and all audio-files will be deleted after the study has been finished. If you do not wish the whole or part of your interview to be included in this study, these can be removed from the data before the data analysis begins. A number/pseudonym will be used to refer to individuals instead of names when the interviews are typed up and analysed, and we will ensure that no individual is identifiable.

The study reports will only include brief anonymised quotes and individual people will not be identifiable from them. In addition, any personal information will be stored in a locked filing cabinet at King's College London to which only the researcher and her supervisors will have access. On completion of the study all data will be securely stored in the KCL archives and destroyed 7 years after the study was completed.

If this study has harmed you in any way you can contact King's College London using the details below for further information:

Professor Emma Ream (Researcher's supervisor)
 Professor of Supportive Cancer Care
 King's College London
 Florence Nightingale School of Nursing and Midwifery
 James Clerk Maxwell Building
 57 Waterloo Road
 London SE1 8WA
 Tel: 020 7848 3011
 Fax: 020 7848 3764

Alternatively you may wish to contact NACC Helpline on 0845 1303344 Monday to Friday, 10.00 am – 1.00 pm or email info@nacc.org.uk

Where do I go for further information?

It is up to you to decide whether to take part or not in this study. If you decide to take part you are still free to withdraw at any time and without giving a reason.

If you do decide to take part you will be given this information sheet to keep and the researcher will contact you as soon as possible. You will be asked to sign a consent form and an appointment will be arranged. A decision to withdraw at any time, or decision not to take part, will not affect the standard of care you receive in any way. If you have any questions or queries, please contact Wladzia:

Email: Wladzia.czuber-dochan@kcl.ac.uk
 Tel: 020 7848 3531
 King's College London
 Florence Nightingale School of Nursing and Midwifery
 James Clerk Maxwell Building
 57 Waterloo Road
 London SE1 8WA

Appendix XV Participants recruitment form - additional information**Fatigue Study Participant Information**

Mr Mrs Ms Miss

Name:

Age:

Tel:

Email:

Address:

Condition: Crohn's Colitis

Years since diagnosed:

Thinking back over the last week how would you rate your fatigue on the scale of 1 – 10, with 0 – no fatigue at all, and 10 – worst fatigue ever.

0 1 2 3 4 5 6 7 8 9 10

If you were selected for the Interview stage would you prefer face-to-face or over the phone (you would not to travel for a face to face interview as the researcher – Wladzia Czuber-Dochan would come and see you at home):

Face-to-face Over the phone No preference

Would you agree for the Interview to be tape recorded: YES NO

Appendix XVI Participants consent form

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet about the research.



Title of Study: Prevalence and nature of fatigue in inflammatory bowel disease.

King's College Research Ethics Committee Ref: *PNM/09/10-93*

- **Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part.**
- **If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.**
- **I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw from it immediately without giving any reason. Furthermore, I understand that I will be able to withdraw my data up to the point of data analysis.**
- **I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the Data Protection Act 1998.**

Participant's Statement:

I _____

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed

Date

Appendix XVII Participants demographic data and disease activity questionnaires

Demographic Questionnaire

How old were you on your last birthday?

Are you: Male ☐ Female ☐

How many years since IBD diagnosis?

How many years since signs of IBD?

How long have you been suffering with fatigue?

On a scale 0-10, what would your fatigue be today?.....

Which condition are you suffering from? Crohn's ☐ Colitis ☐

What is your ethnic origin?

White

White British

☐

Irish

☐

Any other white background

☐

b) Black or British Black

Caribbean

African

Any other black background

Mixed

White and Black Caribbean

☐

White and Black African

☐

White Asian

Any other mixed background

☐
☐
☐
☐

d) Asian or Asian British

Indian

Pakistani

e) Other ethnic group

Chinese

☐

Any other Asian background

☐

Any other ethnic group

☐

What is your current personal status?

Married

☐

Widowed

☐

Living with a partner

☐

Divorced/Separated

☐

Single

☐

What is your current employment status?

Employed full-time

☐

Employed part-time

.....%

☐
☐

Sick leave

☐

Full-time domestic responsibilities

☐
☐

Full or part-time education

Retired

Unemployed

Registered Disabled

☐

If you are unable to work is it because?

- Unable to work due to IBD ☐
 Unable to work due to IBD-fatigue ☐
 Other health problems ☐
 Not applicable ☐

What is your highest level of education?

- | | | | |
|-----------------------------|--------------------------|------------------------------|--------------------------|
| No formal qualifications | <input type="checkbox"/> | A diploma | <input type="checkbox"/> |
| GCSE/O levels or equivalent | <input type="checkbox"/> | A degree | <input type="checkbox"/> |
| A levels or equivalent | <input type="checkbox"/> | A postgraduate qualification | <input type="checkbox"/> |

What is your present or former occupation / profession?

Do you have dependents / caring responsibilities?

Yes ☐ No ☐

If Yes, whom for?

Children	Parents	Elderly relatives	Friend/Neighbour
<input type="checkbox"/> How many?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How would you describe your accommodation?

- Home owner ☐
 Living in temporary accommodation ☐
 Renting ☐

Do you have any other health problems?

Yes ☐ No ☐

If Yes, what other health conditions/health problems do you have?

Are you currently on any medication?

Yes ☐ No ☐

If Yes, please provide below all the details (Name, dose, and frequently):

SIMPLE INDEX OF CROHN'S DISEASE ACTIVITY (Harvey & Bradshaw 1980)

SIMPLE CLINICAL COLITIS ACTIVITY INDEX (Wajsbøl et al 1998)

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Appendix XVIII Reflective journal and field notes from data collection and analysis

Selected examples - Field Notes from data collection

Interview 1 – William, Ulcerative Colitis (UC), 08/10/2010

I thought carefully about what to wear for today's interview, wondering what William and his wife will think of me. I've decided on trousers and a simple top. I feel excited that finally I am at the stage of data collection. The drive took 1 hour 40 minutes covering just 24 miles – I hope I won't need to take such busy roads at pick time too often. I've arrived at the address and I am 30 minutes early, so have time to put my thoughts together and focus on what I want to achieve. I rang the school secretary and left my mobile number and the interview address with her. I am excited but also apprehensive at the same time. I hope that William will be happy to share his experience with me. I have double checked the recorder. I am ready.

Sitting in the car after the interview I think that it went well. William talked a lot and did not need many prompts. I think that I may have cut him off a few times with my questions. I need to be more careful next time and give more time to finish talking. The interview was quite long 1.20 minutes. William does a lot of activities for a 'fatigued' person. It is interesting that he had a great problem separating fatigue from colitis. He said it is 'part & parcel'.

I have tried my best to concentrate on what he was saying, but occasionally when I looked at the list of points (notes taken during the interview), for a short period of time I may not have heard everything he was saying. I wonder if I have missed anything and if I would then ask different questions? It was rather long interview, so hopefully he had enough time to share his experience.

With the car journey and the interview no wonder I feel tired. I wonder if I used any directing questions? I did mumble a bit at times but this did not seem to affect the clarity or sense of the questions or his answers. He appeared quite relaxed most of the time. He does so much and many different activities with fatigue, I wonder what he could do without fatigue.

13/10/2010

I had two interviews booked for the 14/10 and one for the 15/10/2010. One of tomorrow's participants is unwell (cold) and she wants to re-schedule. Friday's participant has just got out of hospital and he wants to re-arrange the date for next week as well. The participant with the cold will come and see me next week (20/10) and I'll see [...] next Thursday. I must be back on time to attend the Steering Group meeting at 17.30 – 19.30 pm. I am worried that the interview may take much longer than initially thought and I will be late for the meeting.

Interview 2 – Henry, Crohn's disease (CD), 14.10.2010

Henry is coming to see me at 12.00 noon at the University. I hope that he will come. I haven't heard from him to say that he is not coming, so I must assume that he will come. I didn't want to phone him so as not to put too much pressure on him. I need to be more relaxed and not worry as much.

Henry did come for the interview. The interview was held in G.13 not the best room (a bit noisy from the air conditioning) but it was the only room that was available. It took him a good 15-20 minutes to relax and talk about his experience. It was like he almost expected me to ask questions, despite my explanation at the beginning that I would not be leading the interview in any particular direction. I think that he was a bit apprehensive and did not know what to say. It was almost as though he thought that what he had to tell me would not seem important enough to me.

After sometime and few questions asking for more information in relation to what he was telling me about Henry re-assured himself that it is okay to talk about his feelings and problems.

It kind of make sense with what he said to me towards the end of his interview that he does not go to the doctors, he does not get help, he tries to be self-reliant. Talking about his problems is acknowledging the presence of the problems and also acknowledging his weaknesses. Very similar to what the first interviewee said

about being a man is to be strong and healthy and not weak (tired, fatigued) and needing help.

He also does not talk about his IBD and fatigue to his friends and family. His mother does not know about his IBD, (father died of lung cancer a few years ago) and he now does not want to worry his mother about his health problems.

He is also single. I kept thinking that he must be quite isolated and lonely. I felt a bit sorry for him. Is this the right feeling? Surprisingly he referred to being 'old', 'getting old' many times (he is only 46), I kept thinking 'you are not old' you are 'younger than me' and I am not old (I'm 47). I wonder who has more problems with our age – him thinking that he is old or me thinking that I am young?

Interview 3 – Louise, UC, 20/10/2010

Louise was late by 25mins. I thought that she may not come as she either had forgotten or was still not feeling well. This was the shortest interview so far, only 27 mins. Louise was not forthcoming with any extended descriptions in her answers. She was very matter of fact, 'briefly reported' the problem and moved on. It was as though she was afraid to talk more or maybe she had no more to say. She was diagnosed with UC 8 months ago, having suffered for 2 years, 2 years with fatigue – I would think that she would have had many more things to say, particularly as she was so keen to participate in the interview. Maybe I should have asked more questions? It is a very difficult thing to gauge the right balance of questions and the time that the participants will want to talk openly about their problems and issues. She was just not a great talker. Or she was very efficient with her time and words. It will be interesting to see how her experience of fatigue compares to others.

Interview 4 – Robert, CD, 21/10/2010

On my way to the next interview, I have already spoken to Robert on the phone a few times. He is a very good talker, as he contacted me a few times before. Lovely old gentleman. I had to leave home at 7am to catch the train and to be there for 11am. I hope that he will be okay to be interviewed, as he only came out of hospital

last week. I had to re-arrange last weeks' interview with him for this week as he was not well.

Robert is most charming, we spent 1.04 minutes talking until all of a sudden he had to dash to the toilet. But it was after my question 'would you like to add anything else?' to which he replied 'no - I don't think so'. I don't know if his toilet call ended the interview, and had he said everything that he wanted to say? But after he came out of the toilet I double-checked with him if there was anything else that he wanted to say? And he just repeated 'I don't think so'. So I think that we covered everything. At times he was losing his line of thought - was that due to fatigue or his age?

Again when he was talking he kept his eyes closed for a prolonged period of times - did this help him to concentrate or was this a sign of tiredness. I should have asked him. Sometimes I asked him a question that he had not considered before and it took him a few moments to put his thoughts together. At one point he panicked as he lost his line of thought and he asked me to switch the recorder off so as not to waste the battery. I didn't switch the recorder off; instead I asked him if his concentration problem is a sign of tiredness? He found the question interesting, as he did not consider this before.

At the beginning, before we started the interview his wife came to the room and sat on the sofa. I was not sure if I should ask her to leave. It was a bit confusing to me how directive I should be with this sweet old lady. Luckily when I started explaining to Robert how I'll run the interview his wife got up and left. I don't know if she felt protective of her husband or if she was trying to be more social towards me. We did catch-up on the social side after the interview as she had prepared a lovely lunch for all of us (soup, cheese, cake and a glass of sherry). Very sweet people. Robert insisted on taking me to the train station. I was not so keen as at 82 I was not sure how confident at driving he is. But he insisted, stating that he is going to his painting group so he will drop me off on his way. There was no way to refuse.

Both thanked me for visiting them, as it did brighten up their day. They don't get many visitors these days so they are a bit lonely! Is this a cause of depression and

fatigue? I am not questioning the fact of fatigue and the primary cause. I think I would like to understand the contribution of social activity towards fatigue. Is this possible to find out?

Interview 5 – Andrew, UC, 21/11/2010

Went to visit Andrew who lives alone and is a very lonely man. I was 20 minutes late and he had dosed off while waiting. He said that it will take him about 15 min to wake up properly.

Andrew was very sleepy throughout the interview. He closed his eyes on many occasions. He also had problems concentrating and answering my questions at times. I don't know if this was his 'normal' self or was he particularly tired today, although he only marked himself 6 for today's tiredness. He said 'it's' not too bad today.

He talked about not having anyone (no friends or family) in his life. This loneliness and isolation must make his situation even worse. Andrew comes across as being very careful and tight with money. I wonder if he looks after himself properly e.g. cooks and eats properly? He has money because he talked about his savings I had to stop him twice and bring him back to talk about fatigue. His hobby and passion golf had to be abandoned. At the same time he lost the company of people and the sport that he loves, because of fatigue.

He talked about getting frustrated and not having patience for others. I wonder if this is the effect of him separating (divorce) from his wife (30 years ago) or the effect of the illness now or his loneliness and isolation?? Big questions?? I think I need a crystal ball to find the answers. That brings another question! Did he want to be involved in the research so that he would have someone to contact him and have some contact and company, or did he 'just' want to talk about his problem with fatigue. A few people have already talked about being isolated, not having patience for 'idiots', not being interested for small talk, as they have no energy to spare.

Interview 6 – Julie, UC, 26/11/2010

A long trip to see Julie and a very early start. After 5 hours journey (flight and 2 hours by coach) I get to my participant. She picked me up from the bus stop and we travelled another 4-5 miles. There was some snow on the ground from the night before so the weather conditions were not the best. I was not sure if I'll be able to get to the destination but it all worked out and I managed to do the interview.

Julie has 2 large dogs and they were making quite a lot of noise and commotion during the interview. We had to stop twice and Julie went to calm down the dogs. It was very interesting, she was talking about how tired (fatigued) she is but her voice was very strong and very well projected. I wonder if this is part of her theatre training? She lives in the middle of nowhere and this is her husband's chosen retirement place. The scenery is beautiful but I would get depressed from just being so isolated and remote. She only has one neighbour. Julie says that she is very positive person and she comes across as a person full of mental energy and strong will.

It was very interesting when Julie was talking about setting herself targets – low targets so that so that she can achieve them and feel good about herself. She has been living with UC since the age of 8 (for 39 years) and I think that has affected her probably more than she realises. Julie talked about many aspects of her life like work, dealing with doctors and not having enough energy to even try and explain about her fatigue because they are not prepared to listen. She is very philosophical about life and the things around her that are of value to her. It comes down to the fact that human beings actually need very little to survive and to be happy e.g. to have a house in this remote place and to take the dogs for a walk. I think this is what seems to make her happy. I would definitely say she comes across as happy, but at the same time she has given up most of the things in her life.

Problems with her mum (who passed away last year) also influenced many things e.g. the fact that she was not listened to, even accused of lying and not taken to a doctor to be properly tested for her stomach complaints. When she talks to health care professionals mainly doctors and they do not listen or take things seriously then she does not try to convince them, because that is not her aim. Her aim is for

someone to offer her some kind of help and support so that she can deal with her fatigue. For some time now she has been asking to be referred to a dietician, because she feels that the right diet would help her to deal with both fatigue and UC. Low fibre diet helps with UC but it does not give her enough energy, high carbs diet helps with the energy levels but irritates UC. But at the current time she has not been referred for diet assessment (funding cuts).

She talked about retirement and retiring from life, but she is only 47. All this makes me to re-evaluate my life. I am of the same age and constantly planning more and take on more work. I am confused about what life is about and what is/would be a good balance in life?

Selected examples – Reflective notes from data analysis

Data analysis (coding) – Reflection 20/01/2011

All interviews have been transcribed, but before I can start on coding I need to complete NVivo training. Date booked for the two day course – one day in February and one in May. This gives me time to read transcripts and to listen to the recordings of the interviews. The first few interviews that I have listened/read through bring me back to each of the interviews. I can ‘see’ each of the participants as they were on the day of the interview. My photographic memory may come very useful in remembering all the non-verbal points.

Data analysis (coding) – Reflection 17/02/2011

I’ve transferred all the data into Nvivo and started coding. I need to refer to my notes to keep track of the different stages of creating files, codes, etc... With electronic coding it takes a long time – about a day per transcript. I can’t imagine how people can do this by hand. Using Nvivo means that all the data is in one place, no need to worry about cutting strips of paper and arranging them and rearranging to create themes.

Data analysis (coding) – Reflection 17/09/2011

All data coded, but it is a very time consuming process. With having only few days per month to spend on the Phd it is even slower. I start feeling quite tired with all the traveling and my normal work. I feel more tired than ever before – but I don't think I'm fatigued. I don't think I can compare myself to the experience of the participants from the study.

Data analysis – Reflection 9/11/2012

Reflection - It has been a good few months since I worked with the data and I feel that I have to re-read all the transcripts, but instead of reading each transcript, I will read the quotes under each code and only then will I be able to re-group and collapse the codes. **Actions:** time to re-read, quotes in each code, code reduction.

Reflection - I have printed all the codes and cut them into strips to re-arrange them into categories. **Actions:** category creation.

I have put all the codes onto flipcharts (x3)

I have the following categories: (no particular order)

- How to deal with Fatigue – this category incorporates **physical** (activity, breaks), **psychological** (acceptance, fight it – name- acceptance, attitude, dilemma, adaption, give in) and **educational** awareness of fatigue, getting to know yourself, learn more about fatigue.
- HCP – IBD nurses GP, NACC, others – this category is not clear – what HCPs are about (need to re-read this code quotes) if this is a group who help patients or not?
- What others think about fatigue – professionals, patients themselves, friends, family, employers, colleagues. It is not clear if this is about what 'others' think or who are the other significant people in a patients' life who play an important role in helping them to manage fatigue and/or their life. Need to clarify this concept/category. **Action:** to re-read the quotes, to clarify.

Analysis of Data – Challenges – Reflection 19/9/2013

- Difficulty of stepping out of the data and seeing the broader picture
- Individual participants stories are very powerful and I feel a great responsibility to give them a voice, not to cut/omit important points
- Constant iterative process is seen as a positive in re-examining of data, but it is also a negative – constantly returning back to the beginning – showing the overall progress of data analysis and summarising it

21/11/2013 Analysis of Data – Structural Coding – Reflection

- Cross tabulation helps to discover different meanings and contexts.
- **Pattern of fatigue** related to structure of the day (when working and not working?).
- **Routine** can help if built around the pattern of fatigue and can add to the severity if people have no choice/no control over their routine.
- **Sleep** as a way to manage fatigue and reboot your energy or be positive ; the end result of losing your bottle and losing it (negative).
- **IBD diagnosis** of fatigue depending on what was presenting itself first, it impacted on people differently; duration: acute/Crohn's fatigue is this a type or a pattern of fatigue?
- **Fatigue** for many people is just a 'word' something that is there, they do not try to define it or to analyse it too much, but they know that it (fatigue) affects them to a larger or lesser extent and they tend to concentrate on the effect of fatigue on their lives more than on the fatigue itself.
- **Because my body has failed me** it's unreliable to others resulting in a constant battle.
- **Because there is no help & support for people with Fatigue** they have this fatalistic approach to it that it will not get better.
- **The nature of the condition** (IBD) and the impact fatigue has on people's lives makes them very isolated.

- **To recognise fatigue as one of the symptoms** of IBD so that patients will know what they are dealing with. This will reduce their stress.
- **Some people are not diagnosed** with IBD for many years. This leads to them to go through very difficult experiences leading to them becoming broken people, being disbelieved by others and they doubt themselves.
- **When you give up everything** because you can't manage to do it anymore, it takes too much energy but presents you as accepting it (fatigue – submissive) then you can still present this as being in control. You have no life because you gave everything up. But you can't lose anything and that way try and be in control. She just sits on the sofa all day and watches TV and listens to music but 'how lonely am I' is this normal for them? but it is not a normal life.

Appendix XIX Ethics Research Committee approval letter

Wladzia Czuber-Dochan
 Florence Nightingale School of Nursing & Midwifery
 James Clerk Maxwell Building
 57 Waterloo Road
 King's College London
 SE1 8WA

21 April 2010

Dear Wladzia

PNM/09/10-93 Prevalence and Nature of Fatigue in Inflammatory Bowel Disease

Thank you for sending in the amendments requested to the above project. I am pleased to inform you that these meet the requirements of the PNM RESC and therefore that full approval is now granted.

Please ensure that you follow all relevant guidance as laid out in the King's College London Guidelines on Good Practice in Academic Research (http://www.kcl.ac.uk/college/policyzone/attachments/good_practice_May_08_FINAL.pdf).

For your information ethical approval is granted until **21 April 2014**. If you need approval beyond this point you will need to apply for an extension to approval at least two weeks prior to this explaining why the extension is needed, (please note however that a full re-application will not be necessary unless the protocol has changed). You should also note that if your approval is for one year, you will not be sent a reminder when it is due to lapse.

If you do not start the project within three months of this letter please contact the Research Ethics Office. Should you need to modify the project or request an extension to approval you will need approval for this and should follow the guidance relating to modifying approved applications:
<http://www.kcl.ac.uk/research/ethics/applicants/modifications.html>

Any unforeseen ethical problems arising during the course of the project should be reported to the approving committee/panel. In the event of an untoward event or an adverse reaction a full report must be made to the Chairman of the approving committee/review panel within one week of the incident.

Please would you also note that we may, for the purposes of audit, contact you from time to time to ascertain the status of your research.

If you have any query about any aspect of this ethical approval, please contact your panel/committee administrator in the first instance (<http://www.kcl.ac.uk/research/ethics/contacts.html>). We wish you every success with this work.

With best wishes

Yours sincerely

Jim Summers
Senior Research Ethics Officer

c.c.

Dr Emma Ream
Florence Nightingale School of Nursing and Midwifery
King's College London
5th Floor Waterloo Bridge Wing
Franklin Wilkins Building
150 Stamford Street London

Appendix XX Letter of support from Crohn's and Colitis UK

(Previous name National Association of Colitis and Crohn's NACC)



**National Association
for Colitis and Crohn's
Disease**

4 Beaumont House
Sutton Road, St Albans,
Herts. AL1 5HH

Administration & Press:
01727 830038
Information Line:
0845 130 2233
Fax: 01727 862550
Email: nacc@nacc.org.uk

Website: www.nacc.org.uk

3 March 2010

To: Chair of Research Ethics Sub-Committee PNM RESC
Re: Prevalence and nature of fatigue in Inflammatory Bowel Disease

This letter is to confirm that KCL are conducting this study in collaboration with The National Association for Colitis and Crohn's Disease, who are the grant holders for funding from the National Lottery Big Lottery Fund. The lead researcher for this study is Wladyslawa Czuber-Dochan, Graduate Nurse Research Fellow.

Participants in this study are to be recruited as NACC members not as NHS patients.

Participants for phases 1-3c of the study will self-identify by responding to a request in NACC News, the quarterly newsletter produced by NACC and circulated to all 30,500 NACC members. Members who express an interest will be sent additional information and asked to give written and signed consent before taking part in the study.

Potential participants for phase 3d will be randomly selected from the NACC Membership database by NACC's Membership and Database Manager, who will arrange for invite letters from the Project Manager (employed by NACC) to be posted. The mailing list will be anonymous to the researcher (W C-D). Participants who agree to complete the questionnaires will be allocated study ID numbers by NACC and remain anonymous to the researcher (W C-D).

NACC members will be free to withdraw their involvement at any time, including the withdrawal of data up to the point of data analysis. Withdrawal from the study at participants request will be managed by the NACC Project Manager.

Support is available from NACC for any participant who feels uncomfortable, embarrassed or upset by talking about their bowel functions or the impact that living with IBD has on their lives. NACC-in-Contact is a confidential supportive listening service provided by NACC volunteers, all who have personal experience of living with IBD. Volunteers for this helpline are specially recruited, trained and supported by NACC staff. NACC members also have access to a network of 70 local NACC Groups.

Yours faithfully

A handwritten signature in blue ink, appearing to read 'H. Terry', with a long horizontal stroke extending to the right.

Helen Terry
Director of Information and Support
h.terry@nacc.org.uk

Chairman: Elaine Steven
Director: Richard Driscoll

Charity Registered in England Number 1117148, Charity Registered in Scotland No. SC038632
A company limited by guarantee in England: company number 5973370.
Registered office: 4 Beaumont House, Sutton Road, St Albans, Herts. AL1 5HH

Appendix XXI Individual participant summaries

Sophie, CD, FL6

Sophie, a 37 year old female, diagnosed with Crohn's disease (CD) just over a year ago. Sophie lives with her husband, works full time, and her fatigue level on the day of the interview was 6, out of possible 10 points. She was *'rather shocked'* when she was told her diagnosis, but then all the symptoms that she was experiencing *'made more sense'*. Initially, she was diagnosed with IBS, but it *'didn't always fit the pattern of IBS'*, so she thinks that she has got both conditions IBD and IBS, but this hasn't been confirmed by her consultant. Sophie's father and her maternal aunt both had CD. Sophie found it hard to come to terms with the diagnosis of a chronic condition, and she worries that she may need to have surgery. She has other health problems (asthma, eczema, arthritis, migraine and depression) so having another chronic condition is a burden for her.

Sophie struggles with everyday physical and mental activities. She *'generally feels quite fuzzy'* and it's hard for her *'to concentrate and focus'*. She often *'yawns in the middle of the day'* and people think she is *'worn out'*. To keep herself *'going throughout the day'*, she drinks *'a lot of caffeine, usually Coke, because coffee doesn't have the same effect'* on her. She thinks that having *'a little power nap of 15 minutes'* in the middle of the day would help, but there is no opportunity to have a nap at work, so she has to *'keep going'*. She makes *'little mistakes'* at work or in whatever she does, but she has *'no energy to be annoyed about little things'*.

Sophie had fatigue before she was diagnosed with CD, but it is worse now as she also has seasonal affective disorder (interview took place in late autumn). She finds it difficult to remember how awake she felt in the summer, because she can't remember many things, and feels, that she is just *'plodding along from day to day'*. She also feels, that she needs to be doing more, but she *'just hasn't got the energy'*.

Three years ago both her parents died, and she has felt depressed and fatigued since then. She felt more fatigued since her diagnosis of IBS and then IBD. She thinks that *'the stress of everything triggered the Crohn's to come out'*. Fatigue feels to Sophie *'like pulling yourself through porridge, like swimming through treacle, everything is a struggle'*. She has some good days and she has some bad days, but the option of *'sitting at home and doing nothing'* is not an option for her. She worked all her adult life, and she refuses *'to give into it'*. Her employer is fully aware of her condition and is very supportive, so are her colleagues. Sophie's husband is *'a massive support, and she could not have managed without him'*.

Sophie would like to lose weight, but has *'no motivation or drive to do so'* and *'pain and aches make exercise difficult. Due to her low fibre diet, she feels that she 'can't eat much healthy food'*.

Andrew, UC, FL6

Andrew is 72 years of age, retired and lives alone. He was diagnosed with ulcerative colitis (UC) 8 years ago and has been suffering with fatigue for the past 3 years. His fatigue level on the day of the interview was 6, out of possible 10 points.

He says that living with UC is like *'living on a time bomb, as you never know when you're going to get a flare up'*. Having a flare up is frightening for Andrew, as at one stage it made him to go to the toilet 23 times in 24 hours. He says that *'it is like a boiling kettle in your stomach, and when suddenly it gets too much, you go to the toilet'*. Quite often he didn't make it to the toilet, so he had to clean up the house and himself. His bedroom is on the first floor and his bathroom is on the ground floor, and this is part of the problem of not making to the toilet on time.

Andrew used to be very active, played 18 holes golf every day, but now has no energy and had to cancel his membership. He says that golf was his life, and now not being able to play makes him depressed and isolated. Also having to go frequently to the toilet, makes Andrew very embarrassed. He used to grow his own vegetables, but now is not able to do it. The small patch of lawn, that used to take him 7 minutes to cut, now takes him 55 minutes. He talks about his lack of energy and his experience of hitting the *'brick wall, like marathon runners'*, when he is not able to do anything, and almost every hour he has to sit down and sleep.

Andrew is also an asthmatic, but didn't have an asthma attack for 10 years, so he does not think this is a reason for his tiredness. Every morning he has to go to the toilet 3-4 times, and *'from about half past ten, eleven everything seems to go all right'*. He does not know if this is just him, his *'body clock'*, or his *'mind'*, or *'is this common thing with the UC?'* Andrew's daily routine is to get up have breakfast, *'dose off'* after breakfast, go to the toilet few times, prepare lunch, sleep again for about 30 minutes, go for a walk for about 45 minutes or exercise in the garden, sleep again for 30 to 60 minutes, then have dinner at 6 o'clock, and then just sit and watch television. Andrew has noticed that in the past 2 or 3 months he has been losing the muscles in his arms, same as before he was diagnosed with UC. He also gets lots of pain in his arms, and in his whole body. Lack of energy and pain stops him from doing things. He finds this experience very distressing and he doesn't know what to do with himself.

William, UC, FL4

William is a 62 year old gentleman, diagnosed with UC 21 years ago. He is married, lives with his wife and works part-time (80% of WTE). He finds living with UC *'quite difficult'*. Recently he has come out of *'quite a bad flare up'* that he had for some time, so now he feels that things are *'starting to get back to what you might term normal again'*. On the day of the interview his fatigue is at level 4 (out of possible 10). Generally, when he has not got the *'obvious symptoms'*, he does not regard himself as being disable, but technically he thinks he is. However, when he has not got a flare up, then he sees himself as *'a person who hasn't got a health problem of that [bowel] nature'*, but, when he has flare ups, then he *'obviously has to acknowledge that'*. He has a tendency to say *'I have got that nasty flare up'*. William wants to get on with his life and is always *'slightly optimistic'* after he had a flare up, that he *'will actually never ever have another one again, because it would be too gloomy to contemplate the fact that probably'* he will.

Over that last few years, William has been getting flare ups *'at least once a year, sometimes twice'* and they last *'quite a long time'*. He doesn't always *'realise'* that he entered a *'bad phase'*, so the flare up maybe going for *'quite a while'* before he seeks help. Sometimes he *'responds quickly to treatment'*; when he is on steroids, it takes five or six weeks, but he will feel tired for a long time afterwards. Tiredness is more worrying symptom for William, because it stops him from *'getting on'* with what he wants to do. He didn't allow UC to stop him completely from doing what he wanted to do, but fourteen years ago he had to retire on medical grounds, as his job at the time required long hours and travel. At the end of the day he had no energy left, he just had to go to bed, so his life was just work and sleep. Since then, he works part-time for a local firm, and he knows all the public toilets on the way to work. His current job gives him some flexibility in terms of working hours, and he can work on line, so it is not as stressful. His sickness record is *'pretty good'*, so he is *'very pleased about it'*. He could stop working now: he is 62, paid off his mortgage and his children left home, but he likes what he does and he is *'pleased to be able to work and cope with the condition'*, even though it is quite severe at times as he has total colitis.

Now, few weeks after his flare up, he still feels very tired, he is able to go to work, but by 17.00 hr he is very tired and often falls asleep in front of television. William knows that because of his age, he won't have as much energy and he won't be able to do as much as twenty years ago, but he doesn't *'accept it in some respects'*. He says, *'I know I have a serious illness, I am just getting over a relapse, I am 62, and I should be slowing down, but I still feel that I should be able to do the same kind of stuff I could do in my 30's or 40's. My perception of myself in terms of physical ability is 'as I'm still somebody a lot younger than I am'. He finds all this 'quite frustrating at times', and he fears of 'becoming more incapacitated, and less able to do stuff'. He has 'this horror of not being able to get on with stuff', and he has 'all these things' that he 'has got to do instead of laying back and relaxing'.*

William fights the condition; he does not go along with it. He *'would tend to just try to carry on as normal'* but he is *'not sure if that's always a good thing'* and maybe he *'should take time off and try and relax a bit'*. William's stress levels are *'quite high during the year because of the condition'*, and he also knows that *'stress plays a large part in terms of having a flare up and how it progresses'*. He thinks that if he could *'get on top of [his] stress levels, than [he] could pre-empt having another flare up'*.

Mark, CD, FL6

Mark, (47), diagnosed with CD 30 years ago. Fatigue level on the day of the interview was at level 6. Mark lives with his partner and previously he worked in IT, but had to give up his job due to fatigue and now he runs his own business and works on part time basis, 20% WTE.

He thinks about CD as a two halves condition: the hardware site with the direct gut symptoms, and the software site where fatigue is, because it's *'much less understood and it's much more difficult to put right'*. Since being diagnosed with CD he had *'three small bowel resections'*. He knows now that fatigue is part of Crohn's, but even when he was a child, before being diagnosed, he was *'always told he was lazy'* and *'never had very much energy'*. Since having his diagnosis he has been told by some doctors that he *'had Crohn's all along'*, others said that he was *'a lazy kid'*.

Fatigue has been a *'real problem'* for Mark for *'the last 6 or 7 years'*. At the time he started to suffer from dizziness, headaches, shortness of breath and aching joints, and his GP diagnosed him with viral infection and signed him off work for a period of time. Mark has been *'up and down ever since'* with the symptoms. He is *'nowhere near as bad now as [he was] five years ago, which was the worst point that [he] had, from the point of fatigue'*. At that time he *'struggled to do anything at all for a period of nine to twelve months'*. His GP tested him for *'all kinds of different things, but nothing came out'*, so diagnosed Mark with ME.

Mark's hospital consultant refuses to link fatigue with Crohn's. Mark says that *the 'current set-up at the hospital seems to be completely based on tick boxes'*. When he says that he is *'experiencing x, y and z'*, but the blood tests come back normal, he is accused of *'making things up'* and was told that *'the symptoms have nothing to do with Crohn's'*. Mark had *'several battles'* with his consultants, but now he has *'given up fighting them, because it takes more energy than it's worth'*. He finds the approach, *'if something doesn't show up in a blood test, then it can't be happening'*, very frustrating. He finds hospital of *'no use whatsoever'* in relation to his fatigue, as their view is *'this is the way things are, and you have just got to live with it'*. Mark feels *'fortunate'* to have his GP on his site, who listens to his complaints. Mark's GP has special interest in chronic fatigue and *'she seems to take all the surgeries with chronic fatigue people and work with them'*.

Mark told me that he *'recently felt well again'*, until thought reflecting on his life, he realised that he *'tailored [his] life to do a lot less than 5 years ago'* and he doesn't do very much. Sometimes, he feels *'as living a normal life, whatever a normal life is'*, but it is because he has reduced what he does, and he reduced his expectations. He says *'every so often that sort of bangs you on the head and say yeah, it's not really as good as you think it is'*. He had to give up his job due to fatigue, anxiety and panic attacks related to his health. If he had something booked to do in a few weeks time, he would get *'so worked up'* about whether he *'will be well enough to do it, that he 'would be too ill to do it'*.

Mark doesn't go out to socialise, but he goes for walks with his dog and goes out with his partner at the weekends.

Vicky, CD, FL8

Vicky, 24, lives with her partner and works full time. She was diagnosed with DC a year ago, and her fatigue level was 8 on the day of the interview. Since being diagnosed, she has problems with medication, as they are not working for her, and she has many side effects. Because of this, she finds living with symptoms of CD very difficult to live with and difficult to work. Vicky had to stop most things that she did before Crohn's. She can't do her hobbies, she has trouble sleeping, trouble eating, trouble socialising. She is 'very tired most of the time', has '*difficulty concentrating at times*', and '*problems maintaining normal life*'.

Fatigue wasn't '*that bad initially*', but '*over the last six to eight months it's been a real problem*' for her. She thinks it could be due to problems sleeping and '*general fatigue from the illness*'. Vicky gets '*very tired very easily*'. She is physically and emotionally very tired. As she has '*problems concentrating on things for long periods*', this create problems at work. She has to limit her activities and plan carefully what she does, because she will become too tired to do anything. She has to manage her '*weekends quite carefully, to make sure that [she] will be OK on Monday*'. Vicky has difficulty to '*drive long journeys*' because she gets tired, so she doesn't visit her family as much as she would like to, because '*they live quite far away*'. She used to be a '*healthy fit person*' and used to '*go to the gym 4-5 times a week for a couple of hours at a time*'. Now, she can't '*even go for a walk*', because she is '*too tired by the time [she] gets home after work, so she just sits on the sofa and watches TV*'. Vicky lost her '*willingness to socialise because it's tiring*' and she '*can't go to pubs and clubs*' because she can't drink alcohol, and she gets tired very quickly. Because of medication and lack of exercise she has put a lot of weight on. She feels '*as a different person*'.

The feeling of '*extreme fatigue*' makes her feel like she '*would not be able to do anything*'. She feels '*very inadequate*', because there are so many things that she would like to do, but can't because of fatigue. She is worried about her further education and career, because '*it is about taking on more responsibility, and that in itself will make [her] more tired*'. She already had to change her job recently as it involved standing for a long time, and she wasn't able to copy with it. She feels like she '*lets people down*', because she is '*not able to things with them*'.

Vicky lost her younger brother following minor surgery few years ago, and now she is worried that she may die. She already had '*5 surgeries on abscesses*' and now she is considering surgery for Crohn's and this '*concerns*' her.

Previously, when she had surgery, her boyfriend used to look after. On occasions, she had to ask him to change her dressings because the district nurse couldn't always get to her. But these were peri-anal wounds and it was making her very uncomfortable. He was '*absolutely fantastic*', but Vicky feels that at the age of 24, she shouldn't need looking after. It makes her feel like she is in her 70's. She feels '*very fortunate*' to have very good relationship with her boyfriend, but she also feels '*inadequate*'.

Catherine, UC, FL6

Catherine is 49, diagnosed with UC 38 years ago and she lives with her 12 year old daughter. Her fatigue on the day of the interview was at 6, but for a day before it was at 10. Until recently (reading the study advert in the IBD leaflet in June and the interview took place in November 2010) she didn't know that fatigue is part of IBD. She finds living with UC very limiting in terms of what she can do. She finds leaving the house *'nerve-wracking'* and even catching a bus to town (few miles journey) gives her anxiety attack.

When Catherine was diagnosed with IBD she was *'about 12'* and she remembers that she *'couldn't get off the settee'* because she *'was so tired'*. Her father *'used to get annoyed'* with her and tell her to *'get moving'* and to *'stop being lazy'*. Her mum was concerned about Catherine's health and she took her to a doctor. At first Catherine was very ill, and lost a lot of blood, so her tiredness was put down to the blood loss. She had *'blood transfusion as a kid and was on a lot of steroids'*, which *'possibly compensated for the tiredness'*. She also lost a lot of weight, and was *'very thin as a kid'*. Through her teenage years, she was *'in and out of hospital'*.

Catherine finds looking after the house overwhelming, and her daughter often helps with the housework or looks after herself, when Catherine is too tired and *'constantly falls asleep'*. Yesterday, Catherine *'had a very bad day and couldn't keep her eyes open'*. She is *'constantly battling'* with herself, to *'keep moving and to do all the things, as nobody else is going to do it'*. Fatigue can *'hit'* her *'anytime, like a sledgehammer'*. Now she doesn't work, but sometime ago when she was working she used to fall asleep at the computer and once she *'fell asleep when talking on the phone'*. Catherine says that her concentration and her memory were affected, and she made many mistakes because of that, and she *'would get annoyed'* with herself and it affected her confidence and self-esteem. She calls the mistakes *'silly little mistakes'*, but the examples of the mistakes that she gave me (e.g. forgetting a deadline for monthly reports, preparing wrong amount of money for transfer) indicate that the mistakes were not so insignificant. Her memory now is *'shocking'* too. She keeps a list for everything because she can't remember. Catherine's concentration is also affected now and she asks me frequently to repeat the question, because she doesn't remember what question I had asked her.

Catherine feels guilty for not *'looking after her daughter properly'* and for not doing things together as other parents do, but she *'just doesn't have the energy'* and she *'can't afford things'*. They have never been on holiday or to a cinema. She can't afford a car, so going *'places is also a problem'*. She can sometime borrow a car from her neighbour. Catherine would like to get a job, sent few applications and had one or two interviews, but as soon as she mentions UC, she feels that people lose interest in her. They say they will phone her, but they never do.

Louise, UC, FL5

Louise is 51, was diagnosed with UC 7 years ago. Her fatigue level on the day of the interview is at level 5. She is married and has five children from the age of 17 to 25. She says that living with colitis is difficult, because she can't plan ahead, and she needs to be near a toilet, she can't eat or drink much and she is tired all the time. She has some good days and some bad days. On a good day it is *'like running at 60% of your body output'* and on a bad day she needs to stay in bed. Concentration is a problem for her, and doing *'just basic housework'* makes her very tired. Mornings are particularly bad for her, so she tries not to do too much in the morning and she takes regular breaks. Afternoons *'are not too bad'*, but she has to rest again in the evenings. Since being diagnosed with UC, Louise also has many aches and pains in her joints, but can't take anti-inflammatory medication because that *'will upset'* her stomach.

Louise says that living with colitis *'it's a game of learning to be very, very patient, and learning to re-style the whole lifestyle'*. It is like *'recovering from a bad flu, you just don't have the energy'*. She didn't know that fatigue is one of the symptoms of UC. Only about two years ago as her colitis got worse, and her fatigue got worse' then she realised fatigue is *'part and parcel'* of UC.

She has changed over the years, as the colitis progressed. In the past she liked to meet with people and *'have a chat'*, now she doesn't *'like going out too late'*, as she gets very tired. Louise used to be very independent and didn't ask people for help, as now, she has learned to ask for help with things like *'doing shopping'* and housework. Even if she would like to *'mop the house from top to bottom'*, she gets *'tired after just doing downstairs'*. She is not afraid to say to people *'I need to lie down for an hour'*, and her husband and her children are very understanding and they will help. Louise's family have realised that the condition is *'sometimes shattering'* for her, and she is more open to say how she feels. Some people think that she is lazy, but it is her *'body that is not letting'* her to do things.

Robert, CD, FL4

Robert, 82 years of age, married and lives with his wife, was diagnosed with Crohn's disease (CD) and uncreative colitis (UC) less than a year ago, and just a few (4-6) weeks ago, his diagnosis was confirmed as CD. His fatigue level on the day of the interview was 4 out of possible 10. His symptoms began *'with pain and plague'* (diarrhoea) with more than *'usual frequency'*. He went to see a doctor (GP) and he was told that he has CD and UC. It was a *'nasty surprise'* for him. The symptoms have intensified, and Robert was *'fleeing to the toilet sometimes every 10-15 minutes'*, he was in *'a considerable agony, weeping, almost screaming with pain'*. At that point he was referred to *'the specialist gastro team in hospital'*, where the diagnosis of CD was confirmed. It was 10 months later, but Robert thinks that it was *'pretty quick'*.

Robert's fatigue, as he says *'an obvious expenditure of energy, mental as well as physical'* was so bad at times, that he didn't have energy to go to bed in the evening, and he slept downstairs in chair. He was at his *'extreme of suffering'* and *'exhaustion'*. Robert likes painting, but he had no *'physical energy to hold a brush'*, and no *'inner energy'* and he lost the *'aesthetic side of things'*. It was depressing for him, but he found a way round it, he learned to defeat it through laughter. He says *'you have to find someone that can make you laugh, have a good interesting discussion or conversation, my son (who leaves away) is very good at telling stupid jokes, same like his father'*. Robert says *'when we have a good giggle [on the phone], my spirits rise immediately'*, and he feels *'much better because of it'*.

Robert's bowels are developing *'a sort of pattern'* and between 2-3 o'clock and 6.00 am he can go to the toilet 6 to 8 times, sometimes 9. On most days his bowel movements will stop between 9 and 10 o'clock. There is also *'less passing of mucus'*, so *'things are generally more comfortable'*. Then he can have 5 or 6 hours *'with no demands at all, which makes life more normal'*.

With Robert feeling less tired now, he is more interested in doing other things like making quince jelly, making bread, *'experimenting with cooking'*, write poetry, and go to local meetings. He is able to drive his car which gives him more freedom. He is able to drive for *'some three quarters on an hour to an hour'*, and then he needs to stop and relax for 10 minutes.

Robert's son was recently diagnosed with cancer, he had chemo therapy and radiotherapy and now he is affected by fatigue, so frequently that they, father and son, *'share the whole idea of suffering [over the phone] and that is a considerable assistance'*. Robert is also *'very lucky that [his] wife is very understanding and supportive'*, and she *'does everything she can, and makes all the allowances for the situation'*. The number people around Robert *'at the moment shrunk to a very small number, it's mainly family and a couple of close friends, and they are sympathetic'*. Most of the people that Robert spoke to, *'have their family member who has suffered one or other of these conditions, so they know something'* about Robert's *'suffering and they understand'* about Robert's *'vanishing or just how [he] just want to sit down, just talk and do nothing else'*.

Fiona, CD, FL7

Fiona, 21 years of age, was diagnosed with CD 4 years ago. She lives with her parents, is single and she is unable to work due to her IBD and fatigue. Diagnosis of Crohn's has *'totally changed'* her life. She *'never even knew'* about Crohn's. When she was fourteen, she *'got very ill and thought that she was dying'*. Everything has changed at that time, school life (as she was unable to study) and relationship with people (because some people can't cope with everything that's going on). Fiona had to be hospitalised several times, *'being in and out of hospital was a nightmare'* for her, and she had to get used to it. She was *'very scared all the time'* and found herself *'upset a lot of the time trying to get to grips with it all'*. She remembers *'having to learn new things about it [CD], and there was always another bit that's gone wrong'*, and all the symptoms that *'come with that'*.

It took three years for Fiona to be diagnosed with Crohn's, so she *'had to go for three years without any treatment'*. As the tests were negative, she wasn't believed about the symptoms and she was *'made to think that [she] was making it up'*. It was very *'depressing and frustrating'* for her. In a meantime she had many problems, she had *'open wounds, was losing weight, was in pain and didn't want to eat anything'*. She says *'I was a skeleton basically, and had no energy, but they [doctors] wouldn't give me anything to help so I just had to struggle on'*. Fiona had a *'few operations to drain abscesses'* and she was referred to different doctors, who tried to find what's wrong with her, but did not confirm any diagnosis, so then they just said *'or well, you must just be very unlucky'*. She is still *'frustrated and angry'* with how long it took for her to be diagnosed.

Fiona remembers being *'exhausted and not having energy'* even before *'being diagnosed and before Crohn's symptoms started'*. At that time she used to do horse riding (which she loved) and help with riding lessons, but often she would have no energy and *'would be too exhausted to do any work'*. She had no energy to do her coursework either, so her grades were affected. Before being ill, Fiona's teachers told her that she could apply to Oxford to do English, but because she missed 'so much school' she *'didn't get the chance to finish any GCSE's'*. She was *'home tutored'* for a period of time as she *'had to leave school because [she] was too tired to go in, and too weak with everything that was going wrong'*. The tutor *'come in for two hours, or an hour and half depending on how tired [she] was, and once he'd gone [she] would be totally drained, and just lie on the sofa for the rest of the day'*.

When Fiona was diagnosed and finally treated, she had a bad reaction to the medication and *'everything went worse'*. She was *'in constant pain, was throwing up all the time, was unable to eat and was really exhausted, and got to the point that [she] couldn't walk, so had to use a wheelchair to get around'*. She developed Crohn's arthritis and often she is in severe pain and needs to use wheelchair. She went from *'being very bubbly, very energetic, to not going out because [she] was too exhausted'*. She lost all her friends and *'felt very lonely, very isolated and hard to be not with the group'*. Only now Fiona started making friends again over the internet. Most of them are older and mature, and it doesn't *'bother them'* that Fiona is ill.

Fiona never had a boyfriend and never been in a relationship. She *'would love to get a part-time job, but without any qualifications and being in a wheelchair, she doesn't think anybody will give her a job'*. Fiona needs to *'work hard'* and it took her a long time to get her *'head into a good place'*. At times she wishes that she *'wouldn't wake up in the morning'*, but her consultant says that *'she is lucky to have all this time to rest'*.

Roger, CD, FL5

Roger, 64 years of age, diagnosed with Crohn's disease less than a year ago. On the day of the interview reported fatigue at level 7. He is retired and lives with his wife. He thinks that living with CD is *'horrible really, as it took them [doctors] to work out that it was Crohn's'*. He was on holiday in Italy, when the symptoms started with swelling of his leg and then his hand. He was treated with painkillers and antibiotics at the time, but *'nobody knew what was really wrong'* with him. Few months later Roger had a swelling of his throat, and he couldn't eat and couldn't swallow, so he went to a doctor again. He was referred for investigations and tests. He can't remember the names of the investigations; they had *'long names'*. He says *'I had a photograph down through my throat and one up my bottom and they decided I had Crohn's and gave me all this medication'*. Roger had an allergic reaction to the medication, his tongue swelled up and he *'nearly choked – nearly died'*. His medication was changed, he cannot remember the names of the medications, but he has *'got it written down'*. He still feels *'really unwell and sick all the time'*, but he takes the medication as directed by a doctor. He used to go to the toilet about 8 or 9 times a day, and now it's only 5.

Roger says that his *'immune system collapsed'* so he caught many infections since. His fatigue developed slowly. He used to be very active and used to go for a walks every morning. He is a walker and he could walk *'15, 20 miles with no problems and never got tired'*, but in the past 6 months he *'couldn't walk more than 500 yards'*. He couldn't do his gardening, and couldn't dig. He got *'really tired all the time, felt really buggered and a bit morose'*. He still feels *'very morose, very sad and a bit self-pitying'*. He used to be *'usually quite cheerful, but not anymore'*, because he *'just feels knackered all the time'*. Roger's muscles became very weak, so his wife came up with an idea of exercising every morning, *'not much, just ten minutes'*. So has been doing the exercises for about three months, and they help. Roger feels better, and now he can again *'walk three miles every morning'* and it only takes him an hour. After the walk Roger feels *'knackered'* and he sleeps in the afternoon.

To Roger, fatigue is about being physically *'knackered'*, and feels like *'an aura round that [he] doesn't want to do anything'*. So he *'has to push himself to do something'*, just *'little things'*, and then he has the satisfaction of *'actually achieving something'*. Roger asked his gastroenterologist for advice on what to do about fatigue, or a book that he could read or a video, to find out what exercises to do, but the doctor *'only said don't overdo it'*. So Roger doesn't have *'much faith in the doctors'* and he thinks that his doctor doesn't *'know what it [fatigue] is all about'*. Roger is going to have another scan, but he doesn't understand what exactly they [doctors] are testing him for, because nobody *'really explains things'* to him, and *'all this correspondence from all these different people, it's all gobbledegook'* to him. He has *'no idea what it means'*.

Roger is *'absolutely convinced that this tiredness will get more manageable'* if he *'can do more and more exercises'*. Currently he put on weight because of steroids, and he feels *'bloody useless'*. Just to do anything, he has *'been reading a lot and doing crosswords, and crosswords are no-no for'* him. Roger's wife is very supportive and understanding and he doesn't know what he would do without her.

Laura, UC, FL6

Laura, 33 years old female, diagnosed with ulcerative colitis (UC) less than 1 year, and reported symptoms of IBD for approximately 18 months. Her level of fatigue reported on the day of the interview was 2 out of possible 10. She lives with her partner and works full time.

Laura was having problems with urgency, frequency, diarrhoea, passing lots of blood while she was still trying to work full time. She ended up *'being rushed into hospital'*. Since her diagnosis she was hospitalised couple of times, which *'really impacted'* on her working life and had *'quite a substantial amount of time off sick this year'*. First time she *'had to have graded return to work'* and had to *'rely on friends, family and her partner to help with mundane daily things'*. When she was severely ill, she was *'struggling even to wash and dress'* herself. Only in the last month or two, she is getting back on *'an even keel again'*. She tries to work full time on *'flexi hours'* and uses annual leave to take long weekends, so in reality she only works four day week, and other days she has to finish early due to feeling tired and other problems associated with colitis and joint pains. She never imagined, she will *'go through something like this'* as she feels *'like it's sort of something that would happen to someone older'*. She is glad that she has *'got a bit more independence back now, as it was difficult not being able to wash and dress'* herself. She was *'so exhausted'*, she *'couldn't stand up in the shower'*, so it was best for her to sit in the bath, but when out of the bath she *'ended up sitting on the floor'* because she couldn't stand up. It was embarrassing and frustrating that she couldn't look after herself. She was angry that *'being quite young'*, she *'shouldn't be going through something like this'*. She felt resentment that she had *'to rely on her mum and partner to do things'* for her.

At the worst stage Laura felt *'beyond tiredness'* and her whole body felt *'exhausted'* and *'even the smallest things just zapped every ounce of energy'* in her. After walking *'a hundred yards or so'* she felt like she *'would run a marathon'*. Prior this she was fit and healthy and use to go running, and now most of the time she feels *'so exhausted, so tired and out of breath'*. She just wants to lie down and sleep all the time. She can't run *'partly because feels so tired and exhausted ... and partly because joints ache and pain'*. Laura had to adapt and now she swims as often as she can, even when she struggles.

Even after a good night sleep she wakes up feeling tired in the morning, and again in the early afternoon she feels quite tired again. She needs to sleep for an hour maybe an hour and half in the afternoon, and she is quite happy to go to bed half nine, 10 o'clock and sleep thought to seven the next day. The beginning of the week is better for her after she had weekend to recover. She sleeps quite a lot at the weekend to recover, but by Thursday feels exhausted again.

Hugh, CD, FL8

Hugh, 39 year of age, single and lives alone in a rented accommodation. He was diagnosed with CD 25 years ago at the age of 15. His fatigue on the day of interview was self-scored at 8. He says that *'it happened at an important kind of stage of life, and it only took six months in all to be diagnosed back then'*. He lost a lot of weight, his *'weight went down to a five and half stone, and he was hospitalised and treated with steroids'*. He had a *'lot of time off school and was doing a lot of school work at home'*. In the next 5 years he had 3 rectal abscesses and *'had to go to hospital to be sorted out'*. His weight at the time improved to *'about seven and half stone, but didn't go up greatly, so it was very difficult to have the energy, so [he] just got on with life'*. At the age of 19 he had a burst intestinal abscess and he needed an emergency re-section. After that he improved *'quite a bit and was quite well for a couple of years'*.

At that time, Hugh got himself an admin job, but it was a *'struggle tiredness wise'* and he had to *'cut down'* on his hours. At the same time he was doing an A-level course. He was also diagnosed with depression and was put on an antidepressant medication. When he was 25 he *'eventually went to university'* and *'coped OK with'* it in the first year as there were *'not many hours per week'*. Hugh did struggle with long days and he could not keep up with some of his work and the social side of things. After completing the university course, he got a full time office (nine to five) job and moved out. But *'very quickly the hours crept up, and went into the evening'*, and then he *'started to struggle a lot'*. For the past ten years Hugh *'found it more difficult to cope with fatigue'* and frequently he *'comes home completely exhausted'*. He only just managed *'to get through the day'*, and *'things in the evening became less and less possible'*. Some 5 years ago he cut down his hours to initially 4 days per week, but eventually he had to cut down to 3 days a week. At the same time his depression *'picked up as well'* and he was unhappy with his job. He felt that everything was a struggle, and he had no social life at all. He had to plan everything weeks in advance. If Hugh *'did anything at the weekend [he] had to book an extra day or two's holiday the following week just to compensate for the fact it was going to take [him] that bit extra to recover'*.

Hugh finds that *'things tend to go in quite a cyclic motion'* for him. He would have a *'bad year with Crohn's and the depression would take a back seat, and then it would work its way round the other way, the depression would kick in once the bowel settled'*. It takes Hugh a *'lot of energy, particular mental energy to deal with all this, and trying not to let it to defeat'* him. Hugh feels very lonely and isolated. He has had few short relationships, but he sees himself as *'broken goods'* and thinks that nobody will want him as he is. He thought that by now, being 39, he would have had a partner and children, but currently he thinks that this will never happen.

He is struggling financially, and cannot even afford to pay for the central heating. He is at risk of losing his job because of his long term sickness and he may need to move back with his parents.

Henry, UC, FL8

Henry, 46 years of age, single, diagnosed with UC four years ago. His fatigue was at 8 out of 10 on the day of the interview. Living with UC is disruptive for Henry. Currently it is not so bad, as he has *'to go to the toilet only three or four times a day'*, but he needs to be *'by a toilet at certain times of the day'*. UC, *'certainly changed'* his life, and made it more difficult but it is not *'too difficult'* compared with some people that Henry knows, who are affected by the same condition.

At the time of registering for the study three months ago, Henry's fatigue was at level 8, but recently he was diagnosed with obstructive sleep apnoea and has a CPAP (Positive Airway Pressure) machine, and now he says that he is *'definitely not as fatigued as [he] was when [he] was diagnosed'*. Henry is not sure whether his fatigue is related to his *'condition, or lack of sleep, or long working hours'*, but *'it's definitely gone down since [he] has been diagnosed and has a CPAP machine'*.

At the time when the fatigue was bad, for some six months or so, Henry was *'almost falling asleep at work, it was always twice a day about 10 o'clock in the morning and then in the afternoon'*. Henry works in IT where a lot of sitting down is involved. Henry was so tired that he was *'basically dropping off to sleep and so he had to force himself to stay awake by going outside to get fresh air or by splashing cold water onto his face'*. Henry was unable to hide his fatigue from his manager as he sat opposite him *'only 10 feet away'* and this *'caused him to feel embarrassed'*. Henry worried that his boss was *'wondering why [he] was falling asleep, and what problems [he] had at home, or why [he] wasn't sleeping enough, burning the candle at both ends or whether [he] was serious about [his] work'* Henry wasn't able to concentrate all the time and he did make some mistakes but he tried *'not to make too many mistakes in a row, so people would start asking questions'*.

For Henry this constant tiredness was a *'mystery'* and it was *'discouraging'*, because he *'didn't know why it was happening'*. At first he thought that it was *'a normal tiredness'* because he worked too much, or that he didn't get enough sleep, or maybe he was getting old. He tried to exercise, but he *'lost all interest and just didn't feel [he] had the energy to do anything else apart from go to work, come home and that was it'*. It was a *'wasted period'* for Henry because, apart from *'working, sleeping and eating'* he *'didn't do anything else'*. He didn't go out much as he had no energy. He started improving now, and he feels that he has more energy. He said *'I'm going out slightly more, I'm starting to think about exercise so, I haven't got back into it yet, but at least I've started thinking about it so, there's a change'*.

Sue, CD, FL9

Sue, 58 years old, diagnosed with CD sixteen years ago. She is married and lives with her husband. Fatigue on the day of the interview was at level 3, and at the point of registering on to the study it was at level 9. Sue finds living with CD very difficult, even when the disease is in remission, because she never knows how many times she will have to go to the toilet. She needs to plan her day, and have to *'pad [herself] up'* if she is going out just in case she would need a toilet and she couldn't get to it. She is not *'too bad with diet'*. There are certain things that she cannot eat, but she knows what they are so that she can avoid them. She is also on a low fibro diet. The worst thing is when CD flares up, but on a day to day basis, when her bowel is *'playing up just a little bit, the worst part is the tiredness, because it just makes [her] head feel woolly and [her] brain doesn't function properly'*. She says *'I walk about like a zombie, I can't sort of concentrate on anything, even the television, reading a magazine and I get very irritable, I feel very miserable'*.

Sue doesn't go out to work because of her illness, but she likes to *'feel [she] is worth something'*, so she likes to *'keep the home going'*. She also feels that because her husband goes to work, she needs to do all the things at home, otherwise *'it would not be fair on him'*. But when the *'tiredness descends on [her], it is very, very difficult to do any jobs'*. She feels that if it wasn't for the tiredness, she would be able to cope. Fatigue *'overwhelms'* her and makes her feel *'quite useless'*. She gets *'very tearful, [her] body feels quite heavy and aches, very similar to minor flu'*. Even when she gets this *'heavy, muffled tiredness, [she] has to – for [her] mental state - do as many jobs as [she] planned'*. Only then she feels good, that it [fatigue] hasn't stopped her.

Sue feels that fatigue comes from her bowel, because *'the bowel is not working properly'*, because even after 7, 8, 9 hours sleep she feels tired. In the morning she is *'very slow, almost as if [she] is drunk, and [her] brain doesn't function'*. She starts the day *'as any normal day but very much slower, and very much heavier, and very much more miserable'*. She doesn't want to *'talk to anybody, and prefer to be alone'*. Tiredness prevents her from being able to concentrate and she finds this very *'frustrating'* and feels like she is *'a bit of a failure'*.

In the past Sue used to go to see her GP, because she felt *'so unwell'*, but he *'used to look at [her] as [she] spoke a foreign language. He is very sympathetic but the tiredness bit just didn't sort of go in, he didn't know what to say, he didn't know what to do'*. He just told her to *'stay in bed'*. When Sue told her consultant that she felt *'very tired, felt spaced out, felt a bit like a zombie'*, he referred her to a psychiatrist. She *'felt annoyed with him, but [she] had no energy to fight back'*. She didn't go to see the psychiatrist, as she didn't feel she needed psychiatric care, she was *'just tired'*. When Sue talked to a nurse, she told her to *'stay on wheat free diet, but it didn't help and was costing a fortune'*. She won't go to *'the doctors now'*, as they *'haven't got a clue about fatigue'*. She deals with it herself, as she knows *'what to do and to expect'*.

Sue and her husband do not go out and they just stay at home. It is sad because she has lost contact with her friends and she can't travel regularly to see her family as they live too far away.

Ruby, CD, FL7

Ruby, 50 years old, diagnosed with CD 6 years ago. Fatigue level on the day of interview was 4 and at the time of registering to the study was 7, out of possible 10. Ruby is married and lives with her husband. She says that living with CD is *'exhausting'*, it completely changes her life. Before her diagnosis she had an active life, *'walked a lot and was very fit'*. Now she doesn't do *'anything physically at all, because [she] gets too exhausted'*. Problems going to the toilet restrict further what she can do, as she needs to be *'near a loo all the time'*.

Ruby *'put on a lot of weight'* and she feels differently about herself. Her husband also says that she is *'a different person'*. About 6 months after being diagnosed (five and half years ago), Ruby had an operation – a resection of a large part of the small bowel, which in Ruby found *'quite traumatic'* and in her opinion made the condition worse. The operation left Ruby with a chronic diarrhoea, which has become *'harder and harder to control'*. She has a flare up at the moment, and she is back on steroids. When she was on steroids previously, she had a *'psychotic episode, psychotic thoughts'*, so at the moment she has been prescribed a low dose. So far she hasn't had any *'psychotic thoughts, but can't see any improvements either'*.

Ruby says that on a bad day *'it is too difficult to even think'*. Ruby prepared some written information before our meeting, because as she said, she is *'too exhausted to think'*. She wants to *'just sit and do nothing, not even read or knit'*. On a good day, she may be able to go shopping for two hours, and then she would get home *'completely exhausted'*. Most of the time she *'just want to chill out'*, so she sits and watches the soaps, because then she doesn't have to think about anything. She doesn't want to talk to anyone on the phone, because it requires energy, it takes afford. Ruby made *'really bad decisions about what [she] was going to do, and what [she] was not going to do'*, whom she was going to talk to, whom she was going to *'bother with'*. The result was that to people that used to know her she can come across as *'quite standoffish and quite rude, but it's because [she] just hasn't got the energy to do it'*. Ruby finds it hard to explain to people even her close family how she feels. She says *'one minute I can be really up, and talking and full of beans, and the next minute I just want to be left alone because it's just the effort of joining in'*.

Ruby used to be the one *'running around'* her friends. Ten years ago she had a party with a hall full of people. Now, as she is more ill and more exhausted, and cannot do things for people, she is left with only one friend, who does all running around for her. All the others *'have disappeared'*. Ruby feels *'really isolated'*, and she doesn't like her life. The only thing that keeps her going is her grandchildren, and the thought of wanting to be the *'best Nana'* for them.

Ruby's husband gets *'really upset'* with her, *'because the fatigue affects every single thing'*. It took them both, but particularly him *'up to this year to accept the fact that she is different now, and can't do things'*. She is not sure if her husband has really accepted her diagnosis. She says *'I still want me back, but I think he definitely thinks he wants me back. But I think I've accepted the fact that I don't think I'll ever be me again ever.'*

Alan, UC, FL10

Alan, 54, diagnosed with UC less than a year ago. Fatigue level on the day of the interview was 5, and 10 at the time of registering with the study. Originally Alan was diagnosed with diverticulitis, but because the symptoms persisted he had further investigations (colonoscopy) and about 6 months later he was diagnosed with UC. Alan says *'I had all the classic symptoms: chronic fatigue, weight loss, lots of bleeding in the back passage, loss of appetite'*. At some point he was going 10, 12 hours with nothing to eat, because he lost his appetite and even smell of cooking would make him feel sick. He says *'it was quite a nasty, not a very pleasant period, and this went on for about a year, year and half'*. When he finally had the diagnosis, it helped him to deal with it, because at least he knew what was wrong with him. The *'only gripe'* that Alan has with the NHS is, that after about 20 minutes consultation with the discharge nurse, when he was told his diagnosis, and medication he needs from his GP, he *'got no explanation of what the disease is, how it's going to affect'* him. He felt *'just left high and dry'* and it's was up to him to do the research, to go to the library or get on the website.

The way that Alan looks at the disease is that if he knows what the disease is and how it's going to affect him, he wants to be in charge of the disease, and do everything to get his *'life back on track again, and not just take tablets and hope for the best'*. In the first two weeks of starting medication it was as if *'somebody had waved a magic wand and all the symptoms just started disappearing'*. He got his energy back, was sleeping better, got his appetite back, and was more positive in himself. But soon *'some of the symptoms started to resurface over several months'*. Then he had to go back on steroids treatment twice in the past eight months. The steroid treatment *'died down'* most of the symptoms, but the one, *'the main remaining symptom is the chronic fatigue'*.

Alan finds fatigue depressing and it gets him down. He compares the experience of fatigue with the experience when he had a glandular fever some years ago. He says *'you feel all right one minute, and then the cycle starts to kick in, and you have to go and lie down'*. He doesn't sleep *'too well'*, partly because he sleeps a lot during the day, because of fatigue. Alan found a pattern between his fatigue and when he has something to eat. If he goes 8 to 10 hours without food, his energy levels are *'pretty constant'*. But as soon as he eats something, he feels *'fatigue creeping up'*. He can't go without food for too long because he is also a diabetic. He tried many things to fight the fatigue, but *'nothing works and everything is waste of time'*. He said *'I'm trying to help myself, there's got to be a solution to overcome this fatigue'*.

Alan doesn't have any social life, does not go out, and does not drive. He is unable to work due to the fatigue and other health problems. His partner is very understanding about he is fatigue, because she has her own health problems and also has fatigue and so she understands, but Alan's family does not *'get it'* and it is *'almost like a taboo subject'*, it is not discussed because *'they feel uncomfortable discussing it'*.

Harry, CD, FL7

Harry, 45 years of age, diagnosed with CD less than a year ago. Fatigue level on the day of the interview was 3 and at level 7 at the time of registering with the study. Harry is married and lives with his wife and two children. CD had *'devastating'* effect on Harry's life, as it *'touches all aspects of his life. He can't live the life that he wants'* to live because of Crohn's. The main problems, apart from the obvious, is *'feeling weak and feeling tired and exhausted'*. The other thing that Harry finds difficult to deal with is *'the prejudice'*, because you can't see the illness, because he looks *'okay'*, people think he is OK. So he had to deal with a lot of prejudice, particularly as he doesn't work now. But he says that he doesn't care *'any more about that'*. Another thing that has been very difficult for Harry is *'that it's taken 12 years to arrive at a diagnosis'*. He says *'I'm on my third gastroenterologist, and the last guy I'd been seeing has been obsessed about seeing ulceration and that was seen for the first time through a capsule endoscopy this January, so I only had a diagnosis this January'*. Having a diagnosis has been *'a massive, massive help'* because Harry felt *'vindicated'* and only now things *'make sense'* why he had been *'feeling ill and under par for so long'*. Harry also feels frustrated that it took so long to be diagnosed and that he was repeatedly let down. He thinks that if he was with his current hospital (university hospital) and not the local general hospital, *'they would have pinned it down much more quickly'*.

Harry says that *'dealing with treatment and side effects is very difficult'*, as the medication that he was on *'messed [him] up and made [him] really ill earlier on this year'*. He is trying a new treatment at the moment, but it's *'not particularly working'*. In terms of medical treatment he has one more option and if that does not work, then next there will be surgery. He finds this *'frightening and very difficult'*.

Another thing that Harry finds very hard, is that for a long time he was *'the bread winner and was at the top of [his] profession'*. But, he couldn't *'keep up and keep going'* at work, and most dinnertimes he *'would go and sleep in the car, in the car park, or in the loo sometimes'*. His bosses thought that he had *'private clients'* and that's where he kept *'disappearing at lunchtime'*. When, in hospital where he worked, they have changed the male and female toilets to unisex toilets, Harry thought it was time for him to go, as it was too embarrassing, to go to unisex toilet, because of smell.

The illness affected Harry's life in a *'huge way, in a massive way'*, as he can't do what he wants to do, and can't be the person, husband and father that he wants to be. Even after 10, 12 or 14 hours sleep he comes downstairs and he doesn't have *'the energy to do anything more than just lie down and watch TV, or sleep or listen to music'*. He doesn't have energy to do even simple things, and this upsets him a lot. He has been treated for depression in the past. Harry has no energy to go out or to go for a walk. When he needs to go to see his GP, he prefers to cycle, but then his neighbours think he is fit to work and should not *'live off his wife'*. Harry says that the illness *'devastated'* his life, but he still tries to see that *'the glass half full'*.

Sally, CD, FL8

Sally, 39, diagnosed with CD less than a year ago. Fatigue level on the day of the interview was 6, and 8 at the time of registering with the study. In February of that year she experienced severe abdominal pain and abdomen distension. In March she was admitted to her local hospital and following blood tests, sigmoidoscopy and CT scan she was referred to a university hospital for a colonoscopy, to confirm the diagnosis. The consultant gastroenterologist was surprised why she was referred for further tests, as her medical information was clearly demonstrating CD. Nevertheless he did the procedure and confirmed that she has had CD and he gave her a choice of going back to her local hospital or to stay under his care. She chose to stay under his care, even that she has to travel further. By May Sally was in a very severe pain, and she was admitted to hospital. For a month a surgeon and a gastroenterologist couldn't identify the cause of her pain. Finally she was diagnosed with a gall bladder stone and was operated on. Post surgery she developed an internal infection and surgery was carried out. It took another month for her wound to heal. She now has a *'big scar at the front that looks like a bum'*.

In the previous year Sally had an operation on peri-anal abscess and two months later she developed a fistula and had to have more surgery. She only recently found out that this was related to Crohn's, but was not told at the time. Four years prior her diagnoses she was hospitalised because of abdominal pain and a distended stomach. It appears to Sally that she had CD for four years, but *'nobody ever was able to diagnose it'*. The past four years has had a *'massive impact'* on Sally's job because of sickness, and she lost her job because of it.

Following the operations Sally has been constantly tired, lost a lot of hair and requires vitamin B12 injections. Sometimes she falls asleep midway through a conversation with people. She feels embarrassed and has to apologise to people about her tiredness. In the past Sally used to get up at six, half past six in the morning, but now she is *'got to the stage that [she] feels like an old age pensioner'*, because she is constantly tired. She never feels refreshed in the morning and her daughter, who is 12, has become her carer. Sally feels guilty that she is not able to look after her daughter properly. Sometimes she even does not see her daughter before she leaves for school in the morning. Recently Sally split up with her partner, and is now waiting for a new flat.

Since Sally's diagnosis, she has put on weight. Before the operations she weighed 15 stone, and now she weighs 18 and half stone. She has always had weight problems because of polycystic ovary syndrome, but since the diagnosis of CD, she has been on steroids and put on 3.5 stone. Sally has been diagnosed with sleep apnoea and will start on a *'sleep machine'* in the next two weeks. Currently she is not allowed to drive, because of the low oxygen blood levels (at 78% while awake), and a risk of falling asleep. She won't use public transport because of a fear of not making it to the toilet on time.

Sally feels as if she is running on a flat battery all the time. She found a part-time job but she is constantly worried about falling asleep. To keep herself awake she drinks a bottle of Lucozade throughout the day, but is struggling with the work.

Sally doesn't feel like a young person anymore, she feels as her *'life has been robbed'* from her.

Julie, UC, FL9

Julie, 47, was originally diagnosed with Crohn's /colitis 14 years ago but recently her diagnosis was confirmed as ulcerative colitis. Julie says that she has had signs of IBD for the last 39 years. On the day of the interview her fatigue was at level 4, but at the time of registering with the study it was 7-9. She is married with no children.

Julie says that the *'most debilitating thing over the time that [she] had the condition has been fatigue'*. She says *'tiredness is virtually constant and that's irrespective of whether I am having a flare up or not'*. She has been to the doctors with *'just tiredness'* but they say that she *'can only have fatigue during flare up and when you are not having a flare up the tiredness has got nothing to do with Crohn's or colitis'*. So she has been living with *'the constant tiredness and certain amount of pain'* since she was eight years old. All the symptoms that are recognised as Crohn's /colitis have been with her since she was eight. Since this time she has been diagnosed with different conditions from appendicitis, to flat feet, to tropical disease, even though she has never been abroad.

For several years Julie has had a lot of abdominal pain. Adapting her diet helped with the pain, but made her fatigue worse. At that point she started going to doctors to deal with her fatigue but often she would be too tired to go to see the doctor or to go to the chemist to pick up the prescription. A year ago she relocated to a different area and because her medical notes were not transferred, she had to go through all the tests again. This time a single diagnosis of UC was made. The test that she had caused a flare up which had carried on for the past 8 months. Julie is confused about her diagnosis, because she has been told different diagnosis by different doctors at different times of her condition. She had been told that she has Crohn's/colitis, then that quiescent pancolitis, recently UC and now she is waiting for the results of a barium tests as they are still looking for a confirmation of CD diagnosis. (My communication with Julie's GP following the interview - with her consent - confirmed that she has UC). Julie says *'I understand that Crohn's is just colitis but through your whole body'*.

On a very good day Julie can work until about 17.00 hours, before she feels really tired, on an average day by three o'clock she would be tired, and on a bad day *'by sort of half past nine in the morning'*. On the bad day it is an effort for her to even think or prepare food for herself. For a long time she thought that her tiredness was related to something other than IBD, particularly if *'everybody'* was telling her that fatigue wasn't part of IBD. Fatigue affects her mental thinking process, so she was wondering whether she is being *'lazy or stupid'* or a different reason altogether? However she now knows, and she listens to her body. If she feels, for example that she cannot be bothered to go and bring a book from upstairs, then that means that her body is telling her something about the state of her fatigue. She knows from her experience of how tired she is on a particular day and what she can do. Basically, she tries to set herself a *'plan for each day, but it will be a very low expectation plan in order to stay happy'*. She likes to set herself a goal that she can *'exceed it every day, so she feels positive about it rather than having a feelings of never achieving anything'*.

Julie used to work full time but now she is self-employed. People say that *'there is nothing wrong'* with her, that she seems alright, but it takes her a lot of preparation to be able to go out and meet with people. She has done some voluntary work over the past few years, but she had to give this up, as she had no energy. *'Now she does what she wants, and doesn't do what she doesn't want to'*.

Gary, CD, FL8

Gary, 51 years old male, diagnosed with Crohn's disease (CD) 11 years ago. He has been experiencing CD symptoms for 25 years, and also reports being affected by fatigue for the past 25 years. On the day of the interview Gary's fatigue level was 7 (on the scale 0-10, with 0= no fatigue and 10 = worst fatigue ever). He works full time and lives with his partner and 1 child from his previous relationship. It took over 10 years for Gary to be diagnosed. During that time he complained of flu like symptoms, bouts of diarrhoea and constipation, iritis, feelings of discomfort in his stomach and aches and pain and tiredness. As he found it difficult to deal with the symptoms he also got *'very depressed'*. The flu like symptoms *'were getting in the way'* of his studying, and was forced to quite as he had *'no energy to do anything'*. And as he says *'nobody put together all these different symptoms, that I might have Crohn's until about 12 years later'*. Also for most of his childhood he was quite a sickly person.

The first treatment suggested to him was acupuncture and herbal medicine as originally he was diagnosed with ME. In the next couple of months he lost *'a lot of weight'*, which resulted in him *'actually collapsing'*. His GP prescribed him antibiotics but because he felt worst the following day, he went back to see his GP. The GP sent Gary to the local hospital for further tests. After x-rays he was sent home by the hospital staff, despite his GP's advice to wait for test results. Gary was too *'worn out'* to argue. An hour later his GP phoned him and told him to go straight back to the hospital, as he had a bowel abscess and needs an operation. When he got back to the hospital he was informed that MRI test confirmed that *'it's not an abscess, you've got Crohn's so you're all right'*.

Gary was traumatised by his diagnosis. He had heard of Crohn's as he knew somebody years ago that had it. That person most of the time *'was absolutely fine'* but *'had really bad episodes of it and had been in hospital for weeks on special diets and medication'*. At the same time he found it easier since the diagnosis, as until then he thought that he *'was dying and nobody was ever going to find out why'*. He said *'I thought I might have cancer, and I felt guilty for feeling like that, you're being self-indulgent and a hypochondriac, and just felt like I shouldn't be feeling like that, but I did'*.

It took Gary a few months to accept the diagnosis of Crohn's and before he started getting help. Before his diagnosis, he went *'to counselling for six months but never opened up to anything, wasn't prepared for it'*. His personal life was affected by his emotional state and his partner left him. Gary's personal *'trauma'* made him *'to wake up'* and *'to deal with all what was going on'* and he felt he was *'a better person... was much more open about feelings, more honest with myself and other people'*. He started to be more responsible about how to manage his own health and to cope better with the symptoms.

Gary had always been *'a responsible person'* and had always gone to work, even though most of the time he felt sick. Even now he feels that it would be so easy not to go to work for *'a couple of days, and then a week, and then two weeks'*. He talked about feeling guilty for wasting medical professionals' time and *'for imagining that, the way he felt was important'*.

Gary sleeps *'really badly'* and wakes up at night. He complains about discomfort in his stomach, aches and pains in all his joints, neck, head, shoulders and all the way down his body.

**Appendix XXII Comparison of terminology used to describe fatigue by
sub-groups: disease type, age, gender, years since IBD diagnosis**

Category	Ways of describing fatigue	
Condition	Fatigue described by CD participants	Fatigue described by UC participants
	<p>trying to run uphill (F1, CD); legs and joints feel like lead (F1, CD); swimming through treacle (F1, CD); brain fog (F1, CD); fighting my head to try and get it to work (F1, CD); struggle (F1, CD); like being on autopilot (F1, CD); like you've never slept (F1, CD); pulling yourself through porridge (F1, CD); knackered (M4, CD); heavy body (M4, CD); body completely drained (M4, CD); so like out of breath (M4, CD); extreme tiredness (F5, CD); my body feels two tonnes in weight (F5, CD); bone weary with no inner energy (M8, CD); really tired (F9, CD); body aches (F9, CD); head feels very woolly, very like fuzzy (F9, CD); I could quite easily flake out (M10, CD); as though I'm being held back (M10, CD); brain is a bit addled (M10, CD); you feel bloody hopeless (M10, CD); you are like a vegetable (M10, CD); like your body is a shell (M10, CD); it's like aura round you when you don't want to do anything (M10, CD); the cogs of your brain have suddenly gone (M12, CD); just a zombie (M12, CD); like having flu (F14, CD); like pulling plug out of the sink, the water just draining away and that's how I feel the energy just draining out of my body (F14, CD); being woolly in thinking (F14, CD); heavy and fluffy and strange (F14, CD); too exhausted to think (F15, CD);</p>	<p>you feel a bit limp (M2, UC); weak (M2, UC); shattered (M2, UC); like running a marathon every day (M3, UC); hitting a brick wall (M3, UC); heavy (F6, UC); twice the weight you are (F6, UC); overwhelming heaviness (F6, UC); hits you like a sledgehammer (F6, UC); head's mince (F6, UC); treadmill of nothingness, in a rut (F6, UC); walking through fog (F7, UC); exhausted (F11, UC); the smallest thing just zaps every ounce of energy in you (F11, UC); you can't do anything (F11, UC); no energy to walk (M13, UC); cloudy brain, empty brain (M13, UC); completely wiped out (M13, UC); wanting to sleep all the time, half awake and half asleep, in a dream world (M13, UC); sluggish (M16, UC); grogginess (M16, UC); head feels like it's feeling up with mush (M16, UC); I have this monster inside me that's laughing (M16, UC); like a demon inside me (M16, UC); trying to flog a dead horse (M16, UC); feeling drunk, hangover effect (M16, UC); can't-be-bothered-ness (F19, UC); physical depression (F19, UC); felling under the weather (F19, UC);</p>

	big black hole (F15, CD); shot at (M17, CD); exhausted and debilitated (M17, CD); no staying power (M17, CD); really lethargic, on top of already feeling dozy (F18, CD); running on a flat battery (F18, CD); seeing things through a fog (M20, CD); very fuzzy about the way that I see the world (M20, CD);	
Age	≤40 year of age	>40 years of age
	trying to run uphill (F1, CD); legs and joints feel like lead (F1, CD); swimming through treacle (F1, CD); brain fog (F1, CD); fighting my head to try and get it to work (F1, CD); struggle (F1, CD); like being on autopilot (F1, CD); like you've never slept (F1, CD); pulling yourself through porridge (F1, extreme tiredness (F5, CD); my body feels two tonnes in weight (F5, CD); really tired (F9, CD); body aches (F9, CD); head feels very woolly, very like fuzzy (F9, CD); exhausted (F11, UC); the smallest thing just zaps every ounce of energy in you (F11, UC); you can't do anything (F11,UC); the cogs of your brain have suddenly gone (M12, CD); just a zombie (M12, CD); really lethargic, on top of already feeling dozy (F18, CD); running on a flat battery (F18, CD);	you feel a bit limp (M2, UC); weak (M2,UC); shattered (M2, UC); like running a marathon every day (M3, UC); hitting a brick wall (M3, UC); knackered (M4, CD); heavy body (M4, CD); body completely drained (M4, CD); so like out of breath (M4, CD); heavy (F6, UC); twice the weight you are (F6, UC); overwhelming heaviness (F6, UC); hits you like a sledgehammer (F6, UC); head's mince (F6, UC); treadmill of nothingness, in a rut (F6, UC); walking through fog (F7, UC); bone weary with no inner energy (M8, CD); I could quite easily flake out (M10, CD); as though I'm being held back (M10, CD); brain is a bit addled (M10, CD); you feel bloody hopeless (M10, CD); you are like a vegetable (M10, CD); like your body is a shell (M10, CD); it's like aura round you when you don't want to do anything (M10, CD); no energy to walk (M13, UC); cloudy brain, empty brain (M13, UC); completely wiped out (M13, UC); wanting to sleep all the time, half awake and half asleep, in a dream world (M13, UC); like having flu (F14, CD); like pulling plug out of the sink, the water just draining away and that's how I feel the energy just draining out of my body (F14,CD); being woolly in thinking (F14, CD); heavy and fluffy and strange (F14, CD); too exhausted to think (F15, CD);

		big black hole (F15, CD); sluggish (M16, UC); grogginess (M16, UC); head feels like it's feeling up with mush (M16, UC); I have this monster inside me that's laughing(M16, UC); like a demon inside me (M16, UC); trying to flog a dead horse (M16, UC); feeling drunk, hangover effect (M16, UC); shot at (M17, CD); exhausted and debilitated (M17, CD); no staying power (M17, CD); can't-be-bothered-ness (F19, UC); physical depression (F19, UC); felling under the weather (F19,UC); seeing things through a fog (M20, CD); very fuzzy about the way that I see the world (M20, CD);
Gender	Male	Female
	you feel a bit limp (M2, UC); weak (M2,UC); shattered (M2, UC); like running a marathon every day (M3, UC); hitting a brick wall (M3, UC); knackered (M4, CD); heavy body (M4, CD); body completely drained (M4, CD); so like out of breath (M4, CD); bone weary with no inner energy (M8, CD); I could quite easily flake out (M10, CD); as though I'm being held back (M10, CD); brain is a bit addled (M10, CD); you feel bloody hopeless (M10, CD); you are like a vegetable (M10, CD); like your body is a shell (M10, CD); it's like aura round you when you don't want to do anything (M10, CD); the cogs of your brain have suddenly gone (M12, CD); just a zombie (M12, CD); no energy to walk (M13, UC); cloudy brain, empty brain (M13, UC); completely wiped out (M13, UC); wanting to sleep all the time, half awake and half asleep, in a dream world (M13, UC);sluggish (M16, UC); grogginess (M16, UC); head feels like it's feeling up with mush (M16, UC);	trying to run uphill (F1, CD); legs and joints feel like lead (F1, CD); swimming through treacle (F1, CD); brain fog (F1, CD); fighting my head to try and get it to work (F1, CD); struggle (F1, CD); like being on autopilot (F1, CD); like you've never slept (F1, CD); pulling yourself through porridge (F1, CD); extreme tiredness (F5, CD); my body feels two tonnes in weight (F5, CD); heavy (F6, UC); twice the weight you are (F6, UC); overwhelming heaviness (F6, UC); hits you like a sledgehammer (F6, UC); head's mince (F6, UC); treadmill of nothingness, in a rut (F6, UC); walking through fog (F7, UC); really tired (F9, CD); body aches (F9, CD); head feels very woolly, very like fuzzy (F9, CD); exhausted (F11, UC); the smallest thing just zaps every ounce of energy in you (F11, UC); you can't do anything (F11,UC); like having flu (F14, CD); like pulling plug out of the sink, the water just draining away and that's how I feel the energy just draining out of my body (F14,CD);

	<p>I have this monster inside me that's laughing(M16, UC);</p> <p>like a demon inside me (M16, UC);</p> <p>trying to flog a dead horse (M16, UC);</p> <p>feeling drunk, hangover effect (M16, UC);</p> <p>shot at (M17, CD);</p> <p>exhausted and debilitated (M17, CD);</p> <p>no staying power (M17, CD);</p> <p>seeing things through a fog (M20, CD);</p> <p>very fuzzy about the way that I see the world (M20, CD);</p>	<p>being woolly in thinking (F14, CD);</p> <p>heavy and fluffy and strange (F14, CD);</p> <p>too exhausted to think (F15, CD);</p> <p>big black hole (F15, CD);</p> <p>really lethargic, on top of already feeling dozy (F18, CD);</p> <p>running on a flat battery (F18, CD);</p> <p>can't-be-bothered-ness (F19, UC);</p> <p>physical depression (F19, UC);</p> <p>feeling under the weather (F19,UC);</p>
Years since IBD diagnosis	≤1 year and less	>1 year
	<p>trying to run uphill (F1, CD);</p> <p>legs and joints feel like lead (F1, CD);</p> <p>swimming through treacle (F1, CD);</p> <p>brain fog (F1, CD); fighting my head to try and get it to work (F1, CD);</p> <p>struggle (F1, CD);</p> <p>like being on autopilot (F1, CD);</p> <p>like you've never slept (F1, CD);</p> <p>pulling yourself through porridge (F1, CD);</p> <p>extreme tiredness (F5, CD);</p> <p>my body feels two tonnes in weight (F5, CD);</p> <p>bone weary with no inner energy (M8, CD);</p> <p>I could quite easily flake out (M10, CD);</p> <p>as though I'm being held back (M10, CD);</p> <p>brain is a bit addled (M10, CD);</p> <p>you feel bloody hopeless (M10, CD);</p> <p>you are like a vegetable (M10, CD);</p> <p>like your body is a shell (M10, CD);</p> <p>it's like aura round you when you don't want to do anything (M10, CD);</p> <p>exhausted (F11, UC);</p> <p>the smallest thing just zaps every ounce of energy in you (F11, UC);</p> <p>you can't do anything (F11,UC);</p> <p>sluggish (M16, UC);</p> <p>grogginess (M16, UC);</p> <p>head feels like it's feeling up with mush (M16, UC);</p> <p>I have this monster inside me that's laughing(M16, UC);</p> <p>like a demon inside me (M16, UC);</p> <p>trying to flog a dead horse (M16, UC);</p> <p>feeling drunk, hangover effect (M16, UC);</p>	<p>you feel a bit limp (M2, UC);</p> <p>weak (M2,UC);</p> <p>shattered (M2, UC);</p> <p>like running a marathon every day (M3, UC);</p> <p>hitting a brick wall (M3, UC);</p> <p>knackered (M4, CD);</p> <p>heavy body (M4, CD);</p> <p>body completely drained (M4, CD);</p> <p>so like out of breath (M4, CD);</p> <p>heavy (F6, UC);</p> <p>twice the weight you are (F6, UC);</p> <p>overwhelming heaviness (F6, UC);</p> <p>hits you like a sledgehammer (F6, UC);</p> <p>head's mince (F6, UC);</p> <p>treadmill of nothingness, in a rut (F6, UC);</p> <p>walking through fog (F7, UC);</p> <p>really tired (F9, CD);</p> <p>body aches (F9, CD);</p> <p>head feels very woolly, very like fuzzy (F9, CD);</p> <p>the cogs of your brain have suddenly gone (M12, CD);</p> <p>just a zombie (M12, CD);</p> <p>no energy to walk (M13, UC);</p> <p>cloudy brain, empty brain (M13, UC);</p> <p>completely wiped out (M13, UC);</p> <p>wanting to sleep all the time, half awake and half asleep, in a dream world (M13, UC);</p> <p>like having flu (F14, CD);</p> <p>like pulling plug out of the sink, the water just draining away and that's how I feel the energy just draining out of my body (F14,CD);</p> <p>being woolly in thinking (F14, CD);</p> <p>heavy and fluffy and strange (F14, CD);</p> <p>too exhausted to think (F15, CD);</p>

	<p>shot at (M17, CD);</p> <p>exhausted and debilitated (M17, CD);</p> <p>no staying power (M17, CD);</p> <p>really lethargic, on top of already</p> <p>feeling dozy (F18, CD);</p> <p>running on a flat battery (F18, CD);</p>	<p>big black hole (F15, CD);</p> <p>can't-be-bothered-ness (F19, UC);</p> <p>physical depression (F19, UC);</p> <p>felling under the weather (F19,UC);</p> <p>seeing things through a fog (M20, CD);</p> <p>very fuzzy about the way that I see the</p> <p>world (M20, CD);</p>
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Appendix XXIII IBD-fatigue - updated literature search and review

Table Updated literature review and included papers (in ascending chronological order)

Source	Aims of the study	Design	Population & sample size	Definition of fatigue & Tools used to measure fatigue	Findings	Study quality
Banovic et al (2012a), France	To identify diagnostic variables of IBD-fatigue using the CART method	Cross-sectional study	118 (26 UC, 92 CD), outpatient	No definition of fatigue provided MFI	<ul style="list-style-type: none"> - The psychological variables have significant influence on fatigue - There is wide diversity of patients' diagnostic profiles - Fatigue should be considered according to profiles that best illustrate its complexity and allow for identifying better potentially remediable factors 	Med
Banovic et al (2012b), France	To determine the relationships between personality and the perception of IBD-fatigue when disease is in remission	Cross-sectional study	135 (22 UC, 59 CD), outpatient	No definition of fatigue provided MFI	<ul style="list-style-type: none"> - Except multiple surgeries, none of the medical variables were linked to fatigue perception - Anxiety and sleep disturbances were the most continuously connected to fatigue perception - Significant relationship between personality categorization on Persistence, Self- Directness and the level of fatigue were observed 	Low
Jelsenness-Jorgensen et al (2012), Norway	To investigate the occurrence of fatigue among IBD individuals in remission that are IBS positive	Cross-sectional study	140 (92 UC, 48 CD)	No definition of fatigue provided FQ	<ul style="list-style-type: none"> - Coexisting IBS-like symptoms among IBD patients in remission are associated with an increased level of fatigue and disease-related worries - Presence of IBS correlated positively with total fatigue scores in UC and CD 	High
Beck et al (2013), Denmark	To investigate how female IBD-patients experience and handle fatigue	Qualitative (design not specified), semi-structured interview	11 (7 CD, 4 UC), outpatients	A persistent and overwhelming sense of tiredness, weakness or exhaustion resulting in a decreased capacity for physical and/or mental work MFI-20	<ul style="list-style-type: none"> - Physical and mental symptoms of fatigue were identified, leading to social, physical and work-related limitations - Emotional consequences of fatigue were: guilty conscience, powerlessness and anger - Patients used planning, prioritising, acceptance, exercise and support to cope with fatigue - Some patients expressed that they had chosen to accept their fatigue 	Low

Source	Aims of the study	Design	Population & sample size	Definition of fatigue & Tools used to measure fatigue	Findings	Study quality
Castillo-Cejas et al. (2013), Spain	To define the applicability of three fatigue questionnaires and to determine the impact of fatigue on health perception in IBD patients	Cross-sectional, two phase study	99 (44 UC, 55 CD) – scale validation 137 (70 CD, 67 UC), 69 HC – to quantify fatigue	The feeling of tiredness with reduced energy levels, decreased muscles strength and cognitive impairment DFIS, FSS, MFIS	- There was a significant correlation of QoL with the three fatigue questionnaires -Significantly higher levels of fatigue were observed in active disease than in remission and HC ($p<0.05$) -Severity of fatigue was significantly correlated with QoL and disease activity	Med
Czuber-Dochan et al (2013b), UK	To explore fatigue, its impact on daily life and the strategies used to ameliorate the symptom	Qualitative epistemologic al interpretive approach Focus group interview	46 (28 CD, 18 UC) members of Crohn's & Colitis UK	An overwhelming sense of unrelenting tiredness, lack of energy, or feeling of exhaustion not relieved following rest or sleep	-Fatigue had a debilitating effect on individual's social and emotional well-being -Employment opportunities were affected by fatigue -People used a range of strategies to cope with fatigue -Fatigue-related issues were poorly understood by clinicians and were not addressed in medical consultations	Med
Costantini & Pala (2013), Italy	To assess the effectiveness of thiamine in fatigue reduction	Open label pilot study	12 (8 UC, 4 CD) outpatient	No definition of fatigue provided CFS Scale	- Out of 12 patients: 10 showed complete regression (score 0) and 2 nearly complete regression of fatigue (score 3 & 5) - The results suggest that fatigue is the manifestation of a thiamine deficiency	Low
Graff et al (2013), Canada	To assess fatigue course and contributing factors longitudinally	Population based cohort study	312 (153 UC, 159 CD)	An overwhelming sense of tiredness and a distinct lack of energy resulting in difficulties with functioning spanning physical and mental domains, MFI	-Participants with consistently inactive disease had the lowest level of fatigue -Fatigue increased over time irrespective of disease activity -Fatigue was higher over time when disease was consistently active -Poor sleep quality, distress, and lower psychological well-being, were significantly associated with changes in fatigue over time. -Women and younger patients were more likely to report higher fatigue	High
Goldenberg et al (2013), Canada	To explore the relationship between iron deficiency and	Cross-sectional study	280 (143 UC, 137 CD)	No definition of fatigue provided MFI	- 49% of individuals with iron deficiency had high fatigue, 45% of individuals without iron deficiency had high fatigue (MFI > 13)	High

Source	Aims of the study	Design	Population & sample size	Definition of fatigue & Tools used to measure fatigue	Findings	Study quality
	fatigue in IBD in the absence of anaemia				-No mean differences in types of fatigue or fatigue outcomes between iron-deficient and iron-sufficient groups. Those with high fatigue had lower mean Hb than those without fatigue, but the difference was not significant -There was no unique contribution of iron deficiency to fatigue after adjustment for active disease and anaemia	
Vogelaar et al (2013), The Netherlands	To assess the disease phenotype and factors related to fatigue in the presence of CD	Cross-sectional study	425 CD patients	CIS-fatigue	- Female gender, disease activity, shorter disease duration, use of anti-TNF at baseline and side-effects to 5-aminosalicylic acid were related to higher fatigue	Med
Cohen et al (2014), USA	To report the prevalence of fatigue in a newly diagnosed IBD individuals and to explore its association with QoL, depression and disability	Cross-sectional study	220 (95 UC, 125 CD), The State CD and UC Area Registry	No definition of fatigue provided FACIT-F Scale	- 26.4% of fatigue prevalent with no difference between CD and UC -Fatigued patients reported more work and activity impairment - IBDQ scores were significantly worse across all dimensions in both CD and UC patients with fatigue - Significantly more women met fatigue criteria than men - Depression was significantly greater in fatigued patients (p<0.001)	Med
Czuber-Dochan et al (2014a), UK	To gain an understanding of HCPs perception of IBD fatigue as experienced by people with IBD	Descriptive phenomenological study	20 HCPs	No definition of fatigue provided	-HCPs identified fatigue as important, but difficult and frustrating symptom to understand HCPs reported that fatigue impacts on emotional, private and public aspects of patients' functioning -HCPs suggested only a few methods to assess and manage fatigue, and they expressed frustration of not being able to help patients more	High
Czuber-Dochan et al (2014b), UK	To develop a fatigue scale specific to the needs and experiences of people with IBD	Mixed-method sequential design	567 IBD, outpatient	A sense of continuing tiredness, with periods of sudden and overwhelming lack of energy or a feeling of exhaustion that is	-IBD-F scale with three sections: section 1- assessing severity of fatigue, section 2 – assessing the impact of fatigue on individual's life, section 3 – a free text section asking for patient's comments and perceived causes of fatigue -The questionnaire had good face and content validity, acceptable to excellent test-retest stability and high degree of internal consistency	High

Source	Aims of the study	Design	Population & sample size	Definition of fatigue & Tools used to measure fatigue	Findings	Study quality
				not fully relieved following rest or sleep		
Kappelman et al. (2014), USA	To evaluate patient-reported outcomes in a cohort of IBD patients	Cross-sectional study	10 634 (3945 UC, 6689 CD); 2079 longitudinal analyses	No definition of fatigue provided PROMIS (including fatigue)	-IBD patients reported more depression, anxiety, fatigue, sleep disturbance, and pain interference and less social satisfaction -Shorter disease duration, active disease, prednisone and having a pouch were associated with worse fatigue, this in turn lead to reduced QoL	Med
Opheim et al (2014a), Norway	To examine fatigue interference with daily living in IBD individuals and to explore relationships between severe fatigue interference and socio-demographic and clinical variables as well as CAM use	Cross-sectional study	428 (190 UC, 238 CD)	A sense of physical tiredness and lack of energy, a non-specific, subjective symptom involving complex interactions between bio-psycho-social and behavioural processes. FSS-5	-39% of the sample reported severe fatigue -Female gender, CD diagnosis, smoking, adverse drug reaction and active disease were significantly associated with higher fatigue -In UC female gender, CAM use, active disease and at least one comorbid condition were significantly associated with fatigue -Patients who were employed, had a higher education level or income were less likely to report severe fatigue interference	High Same study as Opheim et al 2014b
Opheim et al (2014b), Norway	To explore associations between sense of coherence (SOC) and personal characteristics in IBD patients	Cross-sectional study	428 (190 UC, 238 CD)	No definition of fatigue provided FSS-5	-Fatigue score was higher in CD compared to UC patients -Fatigue interference had a strong negative association with SOC	High Opheim et al 2014b
Pellino et al. (2014), Italy	To investigate the impact of fatigue in IBD patients compared with controls	Cross-sectional study	16 IBD, 16 patients with other-than-IBD conditions	No definition of fatigue provided FIS	-Patients with IBD had more severe overall fatigue compared to non-IBD -Severe and moderate disease activity contributed to worse fatigue -Young IBD patients with mild to low active disease showed a trend toward worse fatigue, but results were non-significant ($p = 0.06$)	Med

Source	Aims of the study	Design	Population & sample size	Definition of fatigue & Tools used to measure fatigue	Findings	Study quality
Van Langenberg & Gibson (2014), Australia	To evaluate fatigue prevalence and severity in CD and UC(compared with healthy controls) and to identify potentially modifiable factors associated with different dimensions of fatigue	Cross-sectional study	311 (113 UC, 181 CD, 85 HC) at baseline, outpatient 86 CD individuals at follow-up	A persistent overwhelming sense of tiredness, weakness or exhaustion resulting in a decreased capacity for physical and/or mental work. FIS	-Prevalence of fatigue in CD was 57%, higher than in UC and controls -Active disease, poor sleep quality, mental illness were significantly associated with all the 3 fatigue dimensions -Regular vitamin B group supplementation was inversely associated with physical fatigue - Older age and previous resections were independently associated with cognitive fatigue only -Evidence of use of corticosteroid and regular exercise improved physical fatigue	High
Van Langenberg et al. (2014), Australia	To measure and compare self-reported fatigue with skeletal muscle fatigue in CD subjects and HC and to identify factors amenable to change	Cross-sectional study	27 CD patients and 22 matched HC	No definition of fatigue provided FIS	- CD patients reported greater level of global and physical fatigue than HCs -There was a significant negative correlation, between subjective physical fatigue and objectively measured rate of muscle rate of muscle fatigue -Those reporting greater fatigue via survey tended to demonstrate greater muscle fatigue as tested during exercise on the dynamometer	High
Vogelaar et al (2014), The Netherlands	To assess the effectiveness of SFT on fatigue and QoL in IBD patients compared to CAU	RCT	98 (40 UC, 58 CD)	No definition of fatigue provided CIS-fatigue	- The SFT group had lower (39%) fatigue score than CAU (18%) - SFT also showed significantly better fatigue scores at 3 and 6 months scores ($p < 0.001$) - SFT had a significant beneficial effect on fatigue and QoL, however the effect was no longer significant at 9 months	High
Yoo et al. (2014), Korea	To investigate the fatigue level and fatigue-related factors among Korean IBD patients	Cross-sectional study	128 (68 UC, 60 CD), 92 HC	Persistent, overwhelming sense of tiredness, weakness or exhaustion resulting	-Both CD and UC were associated with greater fatigue score ($p < 0.001$) than HC - In CD, ESR and disease activity were significantly correlated with global fatigue (BFI), but after adjustment none of the factors were statistically significant	Med

Source	Aims of the study	Design	Population & sample size	Definition of fatigue & Tools used to measure fatigue	Findings	Study quality
				in a decreased capacity for physical and/or physical and mental work FACIT-F, BFI	- In UC, anaemia was a significant determinant of fatigue measured by both BFI and FACIT-F. ESR significantly correlated with FACIT-F	
Grimstad et al (2015), Norway	To investigate the prevalence and severity of fatigue in newly diagnosed, untreated IBD patients and to examine relevant disease variables that may influence fatigue	Cross-sectional study	81 (60 UC, 21 CD), 67 HC	An overwhelming sense of tiredness, lack of energy and the feeling of exhaustion that is unaffected by rest, a non-specific, subjective phenomenon interfering with physical, social, emotional functioning, leading to decreased ability to work FSS, fVAS	-Fatigue prevalence in UC was 47% and 42% (FSS and fVAS) and in CD 62% and 48% respectively -Significant relationship was found for both fatigue measures with age and depression - Close to 50% of patients with IBD reported fatigue at the time of diagnosis -In newly diagnosed with active disease, the severity of fatigue was not associated with measures of disease activity	High
McNelly et al (2015). UK	To test the effects of individual advice to increase physical activity and/or supplementation with omega-3 fatty acids on fatigue in IBD	RCT 2x2 factorial study	74 IBD randomised, 52 completed the intervention	No definition of fatigue provided FACIT-F, IBD-F	- There was a significant deterioration of fatigue(FACIT-F) with the supplementation of omega-3 fatty acids- There was no significant difference on FACIT-F scores between those receiving and not receiving exercise advice -Fatigue was significantly reduced in the exercise groups measured by IBD-F scale	Med
Norton et al (2015), UK	To assess three fatigue assessment scales in IBD and to	Cross-sectional study	465/605 responded (164 UC, 301 CD)	A sense of continuing tiredness, with periods of sudden and	-Younger age, female gender, IBD diagnosis, anxiety, depression and QoL were significantly (p<0.001) associated with fatigue on univariable analysis	High

Source	Aims of the study	Design	Population & sample size	Definition of fatigue & Tools used to measure fatigue	Findings	Study quality
	determine correlates of fatigue			overwhelming lack of energy or feeling of exhaustion that is not relieved, or fully relieved following rest or sleep IBD-F, MFI, MAF	-Those working part-time and those not working had higher physical fatigue compared to individuals working full time (IBD-F, MFI, MAF) -All three scales are likely to measure fatigue adequately -Multivariate analysis showed that in IBD-F: 45% of variability of fatigue was predicted by female gender, depression, CD and poorer QoL; MAF: age, depression and IBDQ score were all independently associated with fatigue, 48% of fatigue was attributable to these factors; and in MFI: gender, depression and IBDQ were all independently associated with fatigue, 42% of the variability in general fatigue could be attributed to these factors	
Vogelaar et al. (2015)	To assess the physical fitness and activity in IBD patients and whether fatigue is associated with impaired physical fitness	Cross-sectional study	10 IBD patients with fatigue and 10 without fatigue	No definition of fatigue provided CIS-fatigue	-The patients in fatigue and non-fatigued groups did not differ in regard to medication, clinical characteristics and body composition -Fatigued patients showed significantly lower intensity of daily physical activity and an impaired physical fitness compared with non-fatigued patients	High

Key: **BFI** - Brief Fatigue Inventory; **CAM** - complementary and alternative therapies; **CAU** - care as usual; **CIS** - Checklist Individual Strength – fatigue; **CRP** - c-reactive protein; **DFIS** - Disease Fatigue Impact Scale; **EQ5D** - Euro Quality of Life; **ESR** - Erythrocyte sedimentation rate; **FACIT-F** - Functional Assessment of Chronic Illness Therapy-Fatigue scale; **FIS** - Fatigue Impact Scale; **FQ** - Fatigue Questionnaire; **FSS** - Fatigue Severity Scale; **FSS-5** - Five-Item Fatigue Severity Scale; **fVAS** - Fatigue visual analogue scale; **GSCL (fatigue)** - Short Form Giessen Subjective Complaints List; **Hb** - haemoglobin; **HRQoL** - Health-related quality of life; **IBD-F** - Inflammatory Bowel Disease- Fatigue; **IBDQ** - Inflammatory Bowel Disease Questionnaire; **HC** - healthy controls; **MAF** - Multidimensional Assessment of Fatigue; **MFI** - Multidimensional Fatigue Inventory; **MFIS** - Modified Fatigue Impact Scale; **PFS** - Piper Fatigue Scale; **PBT** – Problem solving therapy; **PSC** - primary sclerosing cholangitis; **PROMIS** – Patient Reported Outcomes Measure; **QoL** - quality of life; **SBS** - short bowel syndrome; **SF-36** – Health Survey Short Form-36; **SOC** - sense of coherence; **SFT** - solution-focused therapy

Appendix XXIV Dissemination plan of findings from IBD-fatigue study

Oral and poster presentations

1. European Crohn's and Colitis Organisation (ECCO) 11th Congress, 16-19 March 2016, Amsterdam, The Netherlands. Poster/Oral presentation Abstract submitted: 'Fatigue as experienced by individuals diagnosed with IBD – a descriptive phenomenological study'.
2. North-West IBD Specialist Nurse Conference, 20 Apr 2015, Manchester. Workshop: 'IBD-fatigue assessment and management'.
3. Dr Falk Symposium, 6-7 Mar 2015, Frankfurt. Poster title: 'Experience of fatigue as reported by patients with IBD – a descriptive phenomenological study'.
4. Crohn's & Colitis UK Annual General Meeting, 07 June 2014, Bristol. Paper title: 'Understanding fatigue in IBD'.
5. Cambridge Falk Forum, 25 April 2014, Cambridge. Paper title: 'Fatigue in IBD: over reported and under managed'. (Invited speaker)
6. The 8th Ferring National IBD Nurse Symposium, 20-21 Nov 2012, NEC, Birmingham. Paper title: 'IBD fatigue – the size of the problem'. (Invited speaker)
7. European Academy of Nursing Science, 09-13 July 2012, Leuven, Belgium. Poster title: 'Fatigue in inflammatory bowel disease, what is it and how can we measure it? A literature review'.
8. King's College London, Research in Action Group, 21st June 2012, London. Oral presentation: 'Fatigue in IBD – what do patients and the literature tell us?'
9. King's College London, Research Symposium, 12th June 2012. Poster presentation 'Measuring fatigue in IBD'.
10. The Crohn's and Colitis UK Charity AGM, 14th April 2012, London. Paper title: 'What do patients and the literature tells us about IBD-fatigue?'
11. The RCN International Nursing Research Conference, 23-25 May 2012, London. Paper title: 'Experience of fatigue in people with inflammatory bowel disease'.
12. The RCN International Nursing Research Conference, 23-25 May 2012, London. Paper title: 'Prevalence, contributing factors and management of fatigue in inflammatory bowel disease: a literature review'.

Publications to prepare

1. Czubor-Dochan W., Norton C., Armes J. & Ream E. (in preparation) Exploring fatigue in IBD as experienced by individuals – a descriptive phenomenological study.
2. Czubor-Dochan W., Norton C., Armes J. & Ream E. (in preparation) Phenomenon of fatigue in chronic conditions and the methods to study it – A meta-study and synthesis of qualitative research in cancer, MS, RA and IBD.
3. Czubor-Dochan W (to prepare) 'To describe or to interpret' – analysis of phenomenological philosophy and its use in studying patients experience.